

SAYING NO CAN BE POSITIVE Spring 2006 (updated 2011)

The following has been designed to support M.E. sufferers who choose to **not** attend the current NHS Chronic Fatigue Syndrome/Myalgic Encephalomyelitis clinics, 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 Therapy. This document may also support M.E. patients who refuse to receive the treatments of CBT and GET recently recommended by NICE for CFS/M.E. and also by the PACE trials (Prof. Peter White et al.) 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 Therapy 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 doesn't have to comply with the recent NICE guidelines on CFS/M.E., supported by the above law, because M.E. is not scientifically in mental health.

3) The NICE guidelines, which support CBT and Graded Exercise Therapy for M.E., are not mandatory. In practise, GPs and all doctors do follow the NICE Guidelines: this is because all NHS organisations have a legal requirement to implement NICE guidance. **However, the treatment aspect is not enforceable.**

'I can clarify that NHS organisations are indeed expected (and in some cases, such as a type of guidance called Technology Appraisal guidance, legally obliged) to implement NICE's recommendations. This is not the same as saying that the NHS has the power to force a patient to undergo a treatment which they do not want.' ²

Also,

'NICE clinical guidelines such as CG53 are not legally enforceable.' ³

4) M.E. patients have a right, under the NICE guidelines, to refuse the recommended treatments from NICE. The following could be used to help M.E. sufferers who wish to refuse NICE's recommendations of treatment:

'Healthcare professionals should be aware that – like all people receiving care in the NHS – people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting other aspects of their care, or future choices about care.' ⁴

A patient's care plan can include state benefits and social services care, which are now also linked with the NICE guidelines.

The NICE guidelines do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of each patient. Healthcare professionals should record their reasons for not following clinical guideline recommendations.

In other words, every patient case is individual and a doctor does have the right to express clinical freedom, along with consulting the patient, as to what is best. This may mean refusing Graded Exercise Therapy and CBT.

5) 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. ⁵

6) 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 Therapy 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 Therapy, a client could claim their 'freedom of expression' has been violated. ⁶ 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 Website: www.dis.org.uk

7) An M.E. patient cannot have their state benefits withdrawn for refusing CBT and Graded Exercise Therapy. Unfortunately, the NICE guidelines are now linked with the awarding of state benefits and Social Services care.

U.K. law says that if a patient refuses suitable treatment without good cause, benefits can be withdrawn.⁷

However, CBT and Graded Exercise Therapy could be argued as unsuitable treatments for M.E. sufferers (see facts below). Scientific opinion which is against CBT and GET for M.E. can be used to obtain state benefits for sufferers.

In addition, NICE has written the following in its CFS/ME Guidelines:

***'Healthcare professionals should be aware that – like all people receiving care in the NHS – people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting other aspects of their care, or future choices about care.'* (This is also quoted in section number 4 of this paper. See Footnote 4 for reference.)**

Although NICE Guidelines are now linked in with the awarding of Social Services care and State Benefits, the above quote can be used in favour of an M.E. sufferer's refusal to undergo CBT and Graded Exercise Therapy.

If sufferers find themselves in a legal battle with their benefits, those who qualify for legal aid may find the following organisation helpful:

the Community Legal Advice Line Tel: 0845 3454345

8) M.E. is a neurological disorder. It has been classified as such by the World Health Organisation in the International Classification of Diseases since 1969.⁸ Therefore psychological therapies could well be inappropriate.

9) 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.⁹ It includes detailed world-wide epidemics of M.E. since 1934 and the viruses which triggered the disease.

10) There are over 2,000 papers showing that M.E. is an organic disorder, according to Prof. Anthony Komaroff (Professor of Medicine at Harvard).¹⁰

11) In November 2010, M.E. sufferers were banned from giving blood. NHS Blood and Transplant has said that the ban is a precaution to protect the donor's safety by ensuring the condition of M.E. is not made worse by donating blood. They say that the move brings M.E. in line with other relapsing conditions such as Multiple Sclerosis and Parkinson's Disease.¹¹ However, many people in the M.E. community feel that the ban is over the possibility of contamination from the virus XMRV, which has been shown in studies to be high in M.E. patients. (See research by The Whittemore Peterson Institute team, published in the journal *Science* 2009.)

12) 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.¹² Although these tests are rarely offered by the NHS for M.E., they have nevertheless shown evidence of physical abnormalities.

13) "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 1984.¹³ Dr. Hyde stresses that M.E. is primarily a disease of the Central Nervous System.¹⁴

14) Patients who respond well to CBT and Graded Exercise Therapy 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.*¹⁵ ***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.***¹⁶ ***The PACE and FINE trials (funded by the Medical Research Council) use the Oxford Criteria.***¹⁷

15) 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.¹⁸ Also, there is evidence indicating pathology of the central nervous system and immune system¹⁹ and evidence of metabolic dysfunction in the exercising muscle.²⁰ Also, Dr. Jay Goldstein has demonstrated through SPECT scans the severely decreased brain perfusion of an M.E. patient 24 hours after physical exercise.²¹ The Canadian Criteria (2003) states that ***the worsening of symptoms after***

exertion is a principal symptom of M.E. ²² Raised levels of noxious by-products of abnormal cell membrane metabolism, associated with exercise and correlating with patients' symptoms have been demonstrated. ²³

16) CBT and Graded Exercise Therapy 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.** ²⁴ 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.** ²⁵

17) The CMO's Report recommended CBT and Graded Exercise Therapy 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.

18) Medical Concerns have been raised about the CMO's Report. The Journal of Chronic Fatigue Syndrome, 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."** ²⁶

19) The NICE guidelines have received widespread condemnation. The recent NICE guidelines were NOT supported by the following registered U.K. M.E. charities: The M.E. Association, the 25%M.E. Group, Invest in M.E., and the Grace Charity for M.E. Also, the organisation BRAME did not support the guidelines outcome, despite the latter serving on the panel. There are many other M.E. groups who also condemn these guidelines. The NICE guidelines received so much criticism that NICE were taken to court by two M.E. sufferers in February 2009. Views from international researchers (e.g. Carruthers, Peterson, Lerner, Hooper and Drs involved with M.E. Research UK) regarding the potential negative effects of Graded Exercise Therapy and CBT, were not acknowledged in the Judge's decision.

Also, the NICE guidelines group had no-one offering a biomedical aetiology (cause) of M.E: therefore, the disease M.E. was never properly addressed by NICE because researchers offering a biomedical cause were not allowed to serve on the guideline group.

"Most Independent M.E. charities and patient organisations have rejected the NICE guidelines..." ²⁷

20) The PACE trials results in February 2011, promoting CBT, Graded Exercise Therapy and APT (Adaptive Pacing Therapy, a form of Graded Exercise) have also received widespread condemnation from M.E. patient groups and medical researchers. ²⁸

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 Quote from Kathleen Jackson-Heppell, Communications Co-ordinator (Enquiry Handling and Internal Communications for NICE), in an email to the Grace Charity for M.E. dated 15/02/2011

³ Quote from Natalie Whelan, Communications Executive (Enquiry Handling) for NICE, in a letter to the Grace Charity for M.E. dated 23rd September 2009.

⁴ NICE guidance document on CFS/ME, Clinical Guideline 53, 22 August 2007, page 8.
<http://guidance.nice.org.uk/CG53>

⁵ See above publication in endnote 1, regarding section attributed to Lord Brandon of Oakbrook, pp.744, 745

⁶ The Human Rights Act 1998, European Convention for the Protection of Human Rights and Fundamental Freedoms, Section 1, Article 10, no.1

⁷ 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.

⁸ World Health Organisation - International Classification of Diseases 10-G93.3

⁹ 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. Also, see www.meactionuk.org.uk

¹⁰ 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. See also www.meactionuk.org.uk

¹¹ See report from BBC NEWS HEALTH, October 8 2010, ME patients face UK ban on donating blood by Michelle Roberts. www.bbc.co.uk/news/health

¹² 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.

¹³ Ibid., A Physician's Guide to Myalgic Encephalomyelitis Chronic Fatigue Syndrome, page 25

¹⁴ 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.

¹⁵ 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.

¹⁶ Katon & Russo, 1992; Freiberg, 1999, Unhelpful Counsel? MERGE's response to the CMO report on CFS/ME, 2002, p15.

¹⁷ See the website of the Medical Research Council at www.mrc.ac.uk

¹⁸ ME and/or CFS paper, September 2001, page 1, V.A. Spence PhD, Chairman of MERGE (ME Research Group for Education and Support). MERGE has become MERUK since this publication (ME Research UK.) This paper quotes from several published findings. Available from MERUK, The Gateway, North Methven Street, Perth PH1 5PP. Also, see www.meresearch.org.uk

¹⁹ The Biology of the Chronic Fatigue Syndrome, Prof. Anthony Komaroff, The American Journal of Medicine 2000: 108: 99-105.

²⁰ Mitochondrial abnormalities in the postviral fatigue syndrome, Behan, W.M.H. et al., Acta Neuropathologica 83, 1991, pages 61-65.

²¹ 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.

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

²³ 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

²⁴ 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.

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

²⁶ See Footnote 22, page 2 of the editorial

²⁷ Letter from liME (Invest in M.E.) to Mr. Des Turner, Chairperson of the APPG (All Party Parliamentary Group) on M.E./CFS, November 2008. Also, see www.investinme.org

²⁸ See Professor Malcolm Hooper's response, 17th February 2011, Professor Hooper's Initial Response to the MRC PACE Trial Press Release hosted by The Lancet www.meactionuk.org.uk

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