SAYING NO CAN BE POSITIVE Spring 2006 (updated 2022, 2024)

This document was originally written in response to the Chief Medical Officer's report in 2002 which triggered the current NHS Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (or encephalopathy) clinics, set up across the country. These clinics may still consist mainly of psychological therapies, such as Cognitive Behavioural Therapy and Graded Exercise Therapy, despite NICE Guidelines 206 stating that GET should not be offered at all and CBT should no longer be offered as a 'cure'. The following may empower sufferers who choose to refuse GET and CBT, or even support their refusal to attend the clinics.
Bedbound/housebound sufferers who are advised to have these therapies on domiciliary visits may also find this document helpful. It may also help those still pressurised to undertake CBT and Graded Exercise Therapy by Private Health Insurers.

Since October 2021, the NICE Guidelines no longer promotes Graded Exercise as a treatment, nor Cognitive Behavioural Therapy as a cure.[1] This is terrific news.

However, the Royal Colleges are still promoting GET and CBT for M.E. sufferers.[2] This is unwelcome news and potentially damaging to sufferers.

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

1)The NICE Guidelines 2021 state that it is not acceptable to recommend a programme of fixed incremental exercise, such as Graded Exercise Therapy to an ME/CFS patient. Nor should any form of physical activity or exercise be presented as a cure: for example, as addressing imputed 'exercise avoidance' and/or physical deconditioning as a perpetuating factor in the patient's ill health. Programmes developed for people with other illnesses, or for healthy people, should not be offered to an ME/CFS patient. [3]

2) The NICE Guidelines 2021 also state that CBT is not a cure for ME/CFS and should not be offered as such. The recent guidelines say that CBT should not be offered on the assumption that sufferers have 'abnormal' illness beliefs and behaviours as an underlying cause of their ME/CFS. [4]

3) The law protects patients from unwanted treatments if the patient is deemed to 'have capacity'. Having capacity is judged by a 4-point test which shows that the patient is capable of making their own decisions.[5] Medical practitioners cannot give a treatment to a patient without the patient's consent, [6] unless they are deemed to be a risk to themselves or to others. If they are judged as 'lacking capacity' then decisions will be made for them by medical staff, allegedly in their 'best interests'.

In practice, 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.' [7]

Also,

' NICE clinical guidelines are not legally enforceable.'[8]

4) M.E. patients have a right, under the NICE guidelines, to refuse any recommended treatments from NICE. The following could be used to help M.E. sufferers who wish to refuse any of 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.' [9]

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.

5) An M.E. patient with a sound mind, no matter how ill they are, can be protected by the following: [10]
There was a legal win in 1998 protecting patients with a sound mind (having capacity), who refused treatment which they were told would help them (see endnote no.6).

Since then, there has since been The Mental Capacity Act in 2005, when patients judged as 'having capacity' can decide for themselves which treatments they do or do not want. **This also includes hydration and nutrition which is now classified as 'treatment' and not as basic care.**

But a patient over 16 years of age who is judged as lacking mental capacity (even temporarily) can have decisions made for them by medical staff. This is meant to be in the patient's 'best interests' but is not always. As well as not giving appropriate medical treatment, a medical team can also stop nutrition and hydration due to the Mental Capacity Act 2005. One way to overcome inappropriate decisions made for M.E. sufferers in this situation, is for a family member/friend to have Lasting Power of Attorney (Healthcare) who can make the decisions for them. To qualify for LPA (Healthcare) the person needs to be over 18 and have capacity at the time of appointing their representative. Similarly, for an Advance Decision to be made by the patient, the patient needs to be over 18. Legally, this leaves 16 and 17 year-olds vulnerable regarding the current law.

Regarding children, medical 'Best Interests' can be carried out under The Children Act 1989: if these clash with the parents of the child, it could end up in court.

6) An M.E. patient has a legal right to oppose CBT and GET. In 2015 there was a landmark ruling which states that a doctor must inform a patient of risks of treatment offered; also, of current research known about the illness being treated and of alternative treatment. [11]

The General Medical Council, in its guidance on consent to medical treatment, advises that a patient must be told of other options to the treatment being offered and the risks and benefits of each option; **then it is for THE PATIENT NOT THE DOCTOR to advise which option they wish to choose.** [12]

7) 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 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.[13] **The UK Law of Human Rights still exists after 'Brexit'; the UK is also still a part of the European Convention of Human Rights after Brexit.**

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

Disability Law Service
The Foundry
17 Oval Way
London SE11 5RR
Tel: 020 7791 9800

Email: advice@dls.org.uk Website: www.dls.org.uk

8) An M.E. patient should not have their state benefits withdrawn for refusing CBT and Graded Exercise Therapy.
The NICE guidelines are linked with state benefits and Social Services; therefore the recent recommendations to not prescribe Graded Exercise, combined with the downgrading of CBT, can support a sufferer to still receive their benefits if they choose to refuse those treatments.

U.K. law says that if a patient refuses suitable treatment without good cause, benefits can be withdrawn.[14]

However, CBT and Graded Exercise Therapy could be argued as unsuitable treatments for M.E. sufferers (see below).

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.)

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

CommunityLegalAdvice.org.uk | Community Legal Advice Tel: 0345 345 4 345

Civil Legal Advice Civil Legal Advice (CLA) - GOV.UK (www.gov.uk) Tel: 0345 345 4 345
Both Community and Civil Legal Advice cover housing and debt issues, including the threat of eviction. They are for those who qualify for Legal Aid.

Also, for general welfare benefit advice: www.turn2us.org.uk Tel: 0808 8022 000

Fightback4justice www.fightback4justice.co.uk help with telephone consultations and advice for putting you in the best position to get your benefit. You do have to pay a small fee to be a member whilst you get their advice. Tel: 0161 672 7444

The organisation Disability Rights UK can also help with benefit guidance and appealing against decisions:

Ground Floor
CAN Mezzanine
49-51 East Road
London N1 6AH
Email: enquiires@disabilityrightsuk.org

www.disabilityrightsuk.org
Tel: 0330 995 0400

SCOPE can help advise on what benefits you are entitled to: www.scope.org.uk
Email: helpline@scope.org.uk
Tel: 0808 800 3333

9) 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.[15] Therefore psychological therapies could well be inappropriate.

10) 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.[16] It includes detailed world-wide epidemics of M.E. since 1934 and the viruses which triggered the disease.

11) In 2015 there were over 9,000 international peer-reviewed papers showing that M.E. is an organic disorder. [17]

12) In November 2010, M.E. sufferers were permanently banned from giving blood; even if a sufferer says that they have recovered, they will still be permanently banned from giving blood. The Dept. of Health 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, or neurological conditions of unknown origin. [18] This decision was made in response to the XMRV (a mouse virus) found in ME/CFS sufferers as published in *Science* magazine 2009.

But it could also be seen as the British Government not wanting to transmit viruses via M.E. patients, suggestive of the fact that they know M.E. is a biomedical disease.

13) 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.[19] Although these tests are rarely offered by the NHS for M.E., they have nevertheless shown evidence of physical abnormalities.

14) "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.[20] Dr. Hyde stresses that M.E. is primarily a disease of the Central Nervous System.[21]

15) 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. Since 1986, there have been at least **25** case definitions of ME/CFS, some of which are criteria used to diagnose[22]***. In the U.K., one criteria is the Oxford Criteria which includes patients with no physical signs and selects subgroups of patients with high levels of psychiatric diagnoses .[23] The PACE and FINE trials (funded by the Medical Research Council) use the Oxford Criteria.[24]***

THE OXFORD CRITERIA HAS BEEN STRONGLY CRITICISED BY THE NIH (U.S. NATIONAL INSTITUTES OF HEALTH) WHO HAVE SUGGESTED THE OXFORD CRITERIA SHOULD BE 'RETIRED' AS IT MAY IMPAIR PROGRESS AND CAUSE HARM. [25]

16) 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.[26] Also, there is evidence indicating pathology of the central nervous system and immune system[27] and evidence of metabolic dysfunction in the exercising muscle.[28] In addition, Dr. Jay Goldstein has demonstrated through SPECT scans the severely decreased brain perfusion of an M.E. patient 24 hours after physical exercise.[29] The Canadian Criteria (2003) states that ***the worsening of symptoms after exertion is a principal symptom of M.E.*** [30]

The International Criteria (2012) go further by stating that **PENE (Post-Exertional Neuroimmune Exhaustion)** is a compulsory symptom for an M.E. diagnosis**.[31]**

'PENE is characterised by a pathological low threshold of physical and mental fatigability, exhaustion, pain and ***an abnormal exacerbation of symptoms in response to exertion. It is followed by a prolonged recovery period.*** Fatigue and pain are part of the body's global protection response and are indispensable ***bioalarms*** that alert patients to modify their activities in order to prevent further damage.'

The authors of the International Criteria panel consist of twelve countries.

In addition, raised levels of noxious by-products of abnormal cell membrane metabolism, associated with exercise and correlating with patients' symptoms have been demonstrated.[32]

17) 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***.[33] 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***.[34]

In 2011, a paper by Tom Kindlon was published in a peer reviewed journal, demonstrating deterioration of M.E. sufferers from GET/CBT. Kindlon's pooled data from several patient surveys, showed that 51.24% of ME/CFS sufferers had been harmed from GET and 19.91% from CBT.[35]

In 2019, a survey by Action for M.E of over 4,000 sufferers, showed that only one in 10 reported that Graded Exercise helped, whist nearly half reported that Graded Exercise worsened their symptoms. Also, CBT made no difference in almost half of the cases and worsened one in five sufferers. [36]

In 2019, a survey of over 2,000 sufferers at Oxford Brookes, reported that the majority of them deteriorated or had no change after GET and CBT. 67.1% were worsened from GET. [37]

18) The 2002 CMO's Report (Chief Medical Officer) 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.

19) Medical Concerns were 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."[38]***

Also, the Canadian Guidelines specifically warn against Graded Exercise programmes.
'Externally based "Graded Exercise Programs" or programs based on the premise that patients are misperceiving their activity limits or illness ***must be avoided.****'*[39]

20) The 2007 NICE guidelines for CFS/ME received widespread condemnation. The 2007 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 condemned 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 from 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 [2007] guidelines...''[40]

21) The CFS/ME clinics were set up after the 2002 CMO's report. In February 2011 the controversial PACE trial results were published, promoting CBT, Graded Exercise Therapy and APT (Adaptive Pacing Therapy, a form of Graded Exercise). The acronym PACE stands for Pacing, graded Activity and Cognitive behaviour therapy; a randomised Evaluation.

The trial was funded by the Medical Research Counsel, Dept. of Health and the Dept. for Work and Pensions, using the Oxford Criteria (psychiatrically prejudiced criteria, see no.15 of this document). The PACE results still have support, unfortunately, amongst some medical practitioners.

In recent years, however, the PACE trial has been seen as ethically flawed and recorded as such by both science journalists and medical researchers. [41]

There are several reasons why the PACE trial is seen to be flawed but the most obvious one is when its authors *changed the assessment outcome* during the middle of their trial![42]

Another crucial point against the PACE trial is that its lead author, Prof. Peter White, is on record as saying that PACE was never meant to be for M.E. sufferers!

In their letter, Peter White et al state: "**The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME"**.

The sentence continues by stating that the PACE Trial studied: "**CFS defined simply as a principal complaint of fatigue that is disabling, having lasted six months, with no alternative medical explanation (Oxford criteria)**". [43]

22) In May 2017 the therapies of GET and CBT were removed from the CDC website (Centers for Disease Control and Prevention USA). The CDC is the leading national public health institute of the USA. [44]

In 2020, The Mayo Clinic also removed GET and CBT from its webpage for M.E. The Mayo Clinic is one of the most famous hospitals in the USA [45]

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

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Also, Professor Ron Davis et al. see page 8 Diagnosis and Treatment of CFS and ME Second Edition 2017, Hammersmith Health Books, Dr. Sarah Myhill

Academic journalist Rebecca Goldin writes in Sense about Statistics PACE: The research that sparked a patient rebellion and challenged medicine March 21 2016
PACE: The research that sparked a patient rebellion and challenged medicine - Sense About Science USA

[42] Diagnosis and Treatment of CFS and ME Second Edition 2017, Hammersmith Health Books, Dr. Sarah Myhill page 9, The PACE study, Chapter One

[43] Initial response by Professor Malcolm Hooper to an undated letter sent by Professor Peter White to Dr Richard Horton, Editor-in-Chief of The Lancet (investinme.org)

[44] In a letter from December 2016, 11 US organisations and 52 advocates called on the CDC to remove CBT and GET references from its website, which they did.

[45] MAYO CLINIC REMOVES GET AND CBT FROM CFS WEBPAGE - #MEAction Network