STATEMENT FROM THE GRACE CHARITY FOR M.E. CONCERNING THE RECENT LANCET REPORT, JANUARY 2015.

Our charity would like to add its voice to the condemnation of the report *Rehabilitative therapies for chronic fatigue syndrome: a secondary mediation analysis of the PACE trial, (Chalder et al., Lancet January 13 2015).* This report is yet another attempt by the Wessely School to undermine both science and the character of M.E. sufferers (Myalgic Encephalomyelitis).

During the PACE trial (White et al., 2011), patients were asked if they agreed with the statement, “I am afraid that I will make my symptoms worse if I exercise.” If they agreed with that statement, they were then labelled as having a fear avoidance of exercise (*The Economist January 17 2015, Fear to tread)*.

The findings of *the Lancet* report were that patient fear of the consequences of CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy) affected the outcome of these two therapies. Or, in laymen’s terms, blame the sick patient if CBT and GET don’t work.

Although the report refers to the condition chronic fatigue syndrome, it is likely that this includes M.E. sufferers. In Chalder’s book *Coping with Chronic Fatigue (1995 Sheldon* Press), M.E. is said to be the same illness as CFS. Certainly, the media are reporting the said *Lancet* paper as patients with M.E.

We believe that M.E. sufferers have every reason to fear activity, but it is a sensible fear due to possible dire consequences. The *Lancet* report overlooks both anecdotal and scientific research which supports M.E. patients’ good reasons to fear exercise. Between 1955 – 2005, there have been over 2,000 papers showing M.E. to be an organic disorder (quote from Prof. Anthony Komaroff)[[1]](#footnote-1), many of these showing abnormal muscle response. Since then, organic illness findings of M.E. have increased abundantly. In 2011, the International Consensus Primer (Carruthers et al.) has included Post -Exertional Neuroimmune Exhaustion (PENE) as a required diagnostic symptom for M.E. This is an international medical acknowledgement of abnormal muscle in M.E. after exercise. In other words, patients feel terrible after exercising and there is a medical reason for it.

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.[[2]](#footnote-2) One of these pooled surveys was from the 25% ME Group for severe sufferers, where 82% of participants said that their illness was worsened by Graded Exercise. 93% reported that CBT had been unhelpful. Some sufferers were not severely ill with M.E. until *after* a course of GET.[[3]](#footnote-3) In our own treatment survey, Graded Exercise was reported as the treatment which caused the most harm to sufferers.[[4]](#footnote-4)

The *Lancet* paper was in part funded by the Departments of Work and Pensions and Health (England). One has to keep vested interest in mind regarding the interpretation of the paper’s results. If M.E. patients can be blamed for being ‘uncooperative’ with GET and CBT programmes due to allegedly ‘proven’ fear, then money can be saved via the reductions of welfare and biomedical investigation.

As a result of the media coverage of this report, M.E. sufferers continue to be unfairly blamed; it can make their relatives sceptical about the illness, causes confusion and further difficulty with welfare, doctors and social services, and condones the waste of public money by printing shoddy, devious research.

Any fear, most likely, lies with the writers of the *Lancet* report, who are being increasingly exposed from reporting inaccuracies about CFS/ME, as more biomedical findings come to light.

They also need to be afraid of possibly breaching an NHS mandate, which states that ICD 10 must be implemented for NHS use. This means that anyone with a diagnosis of M.E. must have it viewed as a neurological disease in the UK.[[5]](#footnote-5)

*The Grace Charity for M.E.*

*24/1/2015*

1. See the paper ‘Illustrations of Clinical Observations and International Research Findings from 1995-2005 that demonstrate the organic aetiology of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome by Hooper, Marshall, Williams, 2005, page 6 [www.meactionuk.org.uk](http://www.meactionuk.org.uk) [↑](#footnote-ref-1)
2. *Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome* Tom Kindlon, Journal of the International Association for CFS/ME Fall Bulletin 2011, Issue 19(2): pages 59-111 [↑](#footnote-ref-2)
3. Analysis Report by 25% ME Group March 2004 [www.25megroup.org](http://www.25megroup.org) [↑](#footnote-ref-3)
4. Treatment Survey, 2011, found under ‘Survey’ [www.thegracecharityforme.org](http://www.thegracecharityforme.org) Out of 53 participants, 9.4% said that GET had made them worse, which made GET the most dangerous treatment to try. [↑](#footnote-ref-4)
5. Since 1995, ICD 10 from the World Health Organisation’s Volume on Nervous Diseases, has been mandated for NHS use. M.E. is listed under the code G93.3 [↑](#footnote-ref-5)