

Your address

Date

Dear (name of MP)

I am contacting you as one of your constituents, using this form letter as I am too unwell to write a more personal one.

I suffer from ME (Myalgic Encephalomyelitis) and I'm concerned that the main NHS treatments on offer for my disease are the psychological therapies of GET (Graded Exercise Therapy), CBT (Cognitive Behavioural Therapy) and antidepressants. These therapies are reinforced by the NICE Guidelines for CFS/ME (CFS stands for Chronic Fatigue Syndrome which isn't necessarily the same disease that I have, of ME.) GET and CBT are also wrongly promoted as a safe treatment from the PACE trial (2011) which has since been shown to be ethically flawed by both science journalists and researchers. <sup>1</sup>Despite this, these therapies are still widely seen as the best treatment for ME with sufferers pressurised to undergo such potentially dangerous programmes.

The ME International Consensus Primer (2011) demonstrates numerous tests which can be performed in aiding a diagnosis for ME, mostly brain scans and immunological markers. <sup>2</sup> Yet none of these are available over here on the NHS.

Scientific research has been ignored in the setting up of the UK CFS/ME clinics, especially the worsening of brain and muscle function after exercise for M.E. patients. <sup>3</sup> International medical opinion and patient surveys have also been ignored which demonstrate that Graded Exercise and CBT are at best ineffective and at worst cause deterioration of M.E. sufferers. <sup>4</sup>

It is contradictory that only psychological therapies are available for ME on the NHS when the Government states that it recognises ME as a neurological disorder. <sup>5</sup> In addition there are over 9,000 international peer-reviewed papers demonstrating that ME is an organic disorder, <sup>6</sup> affecting all three nervous systems as well as the immune, endocrine, cardiac systems and vascular disruption. <sup>7</sup> The World Health Organisation has classified ME as a neurological disorder since 1969. <sup>8</sup> (The WHO is implemented as guidance for many illnesses such as Swine Flu, yet in practice is ignored by this country in its classification of ME as a neurological illness.)

I am concerned because after almost fifty years of the WHO classifying ME as neurological, a psychiatric agenda is pushing to rename ME as BDS (Bodily Distress Syndrome) and/or MUS (Medically Unexplained Symptoms) and have it transferred from WHO's neurological section to mental or behavioural disorders. This would be catastrophic for medical truth, for me personally and all M.E. sufferers. <sup>9</sup>

Reflecting on the above situation, Dr. Sarah Myhill has set up a campaign demanding a public inquiry into the medical abuse in ME sufferers (MAIMES).

**Please can you do one or more of the following to change this dire situation?**

- Sign up to Dr. Myhill's campaign, if you haven't already done so, calling for a UK public inquiry into the medical abuse of M.E. sufferers  
[http://www.drmyhill.co.uk/wiki/Medical\\_Abuse\\_In\\_ME\\_Sufferers\\_\(MAIMES\)](http://www.drmyhill.co.uk/wiki/Medical_Abuse_In_ME_Sufferers_(MAIMES)). You will be given a free book by Dr. Myhill called *Diagnosis and Treatment of CFS/ME*
- Support the need for an ME diagnostic test
- Support the urgent need to change the Dept. for Work and Pensions' definition of ME, which disgracefully categorises it as a psychosocial illness.

- Challenge the Medical Research Council to no longer fund biopsychosocial applications and extend their funding beyond the symptom of only ‘fatigue’; to ask them to fund more biomedical research of ME.
- Challenge the CFS/ME NICE guidelines to acknowledge the WHO’s classification of ME as neurological not psychological
- To ask the CMO to steer the current NHS ME clinics into biomedical, not biopsychosocial centres.

If you could act on either one or more of the above requests, you’ll be doing me and thousands of other ME sufferers a huge favour. Your efforts will be a ray of hope amidst the prejudicial circumstances surrounding ME. Thank you.

Yours sincerely,  
(your name)

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<sup>1</sup> Diagnosis and Treatment of CFS and ME Second Edition 2017, Hammersmith Health Books, pages 8-12, Dr. Sarah Myhill

<sup>2</sup> Myalgic Encephalomyelitis Adult & Paediatric: International Consensus Primer for Medical Practitioners Bruce Carruthers, Marjorie van de Sande ISBN 978-0-9739335-3-6 page 11

<sup>3</sup> 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.

See also, 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

<sup>4</sup> A Physician’s Guide to Myalgic Encephalomyelitis Chronic Fatigue Syndrome, The Nightingale Research Foundation, Vol. 1, Issue 7, revised, 1992, page 25. See also, Analysis Report by 25% ME Group March 2004, [www.25megroup.org](http://www.25megroup.org)

<sup>5</sup> Quote in writing from Ann Keen MP, Parliamentary Under Secretary of State, in a letter to Ann Widdecombe MP, 8 November 2007 for The Grace Charity for M.E. Also, the NHS was mandated to implement the WHO ICD-10 category of M.E. as neurological (see FN 4) on 1<sup>st</sup> April 1995 (letter from Tim Morgan, Dept. Health Customer Services Centre); referenced by Prof. Malcolm Hooper in his letter to Mr. Adam Butler, Dept. of Health 28<sup>th</sup> August 2011. [www.meactionuk.org.uk](http://www.meactionuk.org.uk) Despite this, the NICE Guidelines reject M.E. as a neurological illness.

<sup>6</sup> <http://forums.phoenixrising.me/index.php?threads/the-significance-to-me-cfs-of-the-landmark-change-to-the-uk-law-on-consent.41989/> 9000 peer-reviewed papers on ME/CFS were used to uphold decisions by the Institute of Medicine and the National Institute of Health Pathways to Prevention, USA 2015

<sup>7</sup> Disturbing Discrepancies In Statements Made By Prof. Simon Wessely in relation to M.E./CFS: some questions and answers of which the Gibson Parliamentary Inquiry Needs To Be Aware.

Prof. Malcolm Hooper, Eileen Marshall, Margaret Williams 4<sup>th</sup> January 2006

See also, A New and Simple Definition of Myalgic Encephalomyelitis and a New Simple Definition of Chronic Fatigue Syndrome, by Byron Hyde MD, May 12 2006, as presented at the London Conference

<sup>8</sup> World Health Organisation – International Classification of Diseases 10-G93.3

<sup>9</sup> <http://forums.phoenixrising.me/index.php?threads/icd-11-status-reports-g93-3-legacy-terms-pvfs-bme-cfs.49549/>

*This form letter has been supplied by The Grace Charity for M.E.*