



Promoting effective joint working by ME and CFS organisations to maximise impact on behalf of all people with ME and CFS in the UK

Need for action now to ensure safe NHS care and management advice for Myalgic Encephalomyelitis (ME) patients

People with myalgic encephalomyelitis continue to be at risk of following damaging advice provided by the NHS. This risk is fostered by core recommendations of Clinical Guideline 53 (relevant extracts enclosed); notably, advice to undertake graded exercise, whether with or without a cognitive component - i.e. CBT in the form of graded exercise, with patient 'education' as to why this is deemed suitable. Recommendation 1.9.3.1 on severely affected patients is also of concern in this regard.

As long ago as 2002 the Chief Medical Officer's Working Group recognised that "*substantial concerns exist regarding the potential for harm*" in respect of graded exercise¹, and that patient reports "*clearly indicate that the York review results do not reflect the full spectrum of patients' experience*".²

We do not consider that it is acceptable for this situation to continue unabated pending the publication of the revised guideline, presently scheduled for April 2021.

We are aware that the Health Department in Scotland has recently cautioned against graded exercise 'therapy' - see <https://tinyurl.com/y5txhdv9> (announcement Nov 2020) and <https://tinyurl.com/yyherfp5> (publication August 2020).

We call on the Department of Health to make a similar caution public now in order to help to safeguard patients in England.

We further note that Clinical Guideline 53 does not furnish health or social care professionals with the 'tools' they require in order to comply with a 2015 Supreme Court Judgment³ in this regard. This judgment stipulates that informed patient consent requires the patient to be made aware of "any material risks involved". If professionals are unaware that there is potential for harm, how can they possibly furnish patients with the information required to make an informed decision?

On behalf of Forward ME

Countess of Mar – Chairman Forward-ME

¹ A Report of the CFS/ME Working Group: Report to the Chief Medical Officer of an Independent Working Group. London: Department of Health, 2002; page 47.

² As above, Annex 3: Patient evidence, available to download from the Department of Health website.

³ Montgomery vs. Lanarkshire Health Board [2015] UKSC 11; heard 22nd & 23rd July 2014, judgment given 11th March 2015:

Para 82. In the law of negligence, this approach entails a duty on the part of doctors to take reasonable care to ensure that a patient is aware of material risks of injury that are inherent in treatment. This can be understood, within the traditional framework of negligence, as a duty of care to avoid exposing a person to a risk of injury which she would otherwise have avoided, but it is also the counterpart of the patient's entitlement to decide whether or not to incur that risk.

Para 87 ...The doctor is therefore under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments. The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.

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