

WMMEG (West Midlands ME Groups Consortium)

Herefordshire ME/CFS/FMS Group; Solihull & South Birmingham ME Support Group,
Shropshire ME Group; Walsall ME Link; Warwickshire Network for ME;
and Worcestershire ME Support Group
(website - <http://wmmeg.weebly.com>)

21 July 2011

To: The Countess of Mar, Chair Forward-ME

Dear Lady Mar,

InnovAiT GP Guidelines on 'CFS'

We write further with regard to the important topic of ME/CFS medical education and training and in particular the recently published InnovAiT GP Guidelines on 'CFS' highlighted by the ME Association: www.meassociation.org.uk/?p=6959

It is not clear on this occasion whether any of the M.E. charities have been consulted by the authors prior to publication, however, it *is* clear that there's an imperative for robust and collective action to try and challenge this particularly unhelpful guideline - which we hope you will be able to co-ordinate in your capacity as Chair of Forward-ME.

Whilst some areas of the guidelines *might* be considered to be potentially helpful, such as the general acknowledgement that patients with ME/CFS have legitimate benefit entitlements, we have a number of very serious concerns with regard to definitions, accuracy, interpretations and assumptions (implied or otherwise) which rather than positively contribute to a better understanding of M.E., actually further perpetuate prejudice and misunderstanding. In a number of places we find the language unbelievably, and unacceptably patronising - in fact there are many echoes of the truly awful NICE and NHS Plus drafts that were so fiercely contested by the overwhelming majority of patient groups.

Our specific issues and concerns are identified below:

Definitions (and inaccuracies)

- Not only is there no mention of the heterogeneity of 'CFS', throughout the article, M.E. is assumed to be 'colloquially' synonymous with CFS and after that early 'dismissal', M.E. fails to get any further reference.
- Throughout the guidelines fatigue appears to be used as a lowest-common denominator. As many have stated, including highly respected researcher Professor Leonard Jason, fatigue may not be the main symptom at all!
- It is of course correct for the authors to mention the WHO neurological classification - clearly many years before the surfacing of the artificial and unsatisfactory CFS construct - it is however, clearly not correct to state that there is no neurological evidence!
- We are unclear why there is a reference to '*the Royal College of General Practitioners (RCGP) classifying fatigue within its mental health curriculum statement*' when in 2008, the RCGPs themselves acknowledged to the ME Association (and others) that this was incorrect: www.meassociation.org.uk/?p=408

Leading and unhelpful language

The guidelines are littered with references to 'perceptions' and 'feelings', rather than facts, which can only perpetuate stigma (which they refer to!) misunderstanding and actually serve to reinforce ignorance and prejudice. Perhaps this was the authors' intention...?

'avoiding the habit of checking extensively for physical illness'

*'There is often a **perception** of increased frequency of minor infections...'*

'..mostly **stopped work**'

- * This implies a voluntary cessation of work. Many have been dismissed - often very much against their own wishes.

*'They will **feel** unable to leave the house'*

'There can be a stigma attached to CFS; even medical professionals may negatively stereotype people with CFS.'

'...where the goal is improved function'

- * We find this **grotesquely** insulting. Precisely what other goal would patients have?

Perpetuating factors include : 'Disorganisation' & 'Denial' ?

- * What and where, is the evidence for this statement?!

*'It is important to remember that people with CFS **want** to be taken seriously, so show that you believe them.'*

- * We find this astonishing. Would the same be said to MS patients? This should read: **deserve** to be taken seriously.

'GPs are well placed to make an early diagnosis of CFS and give patients helpful advice to manage their fatigue, hopefully avoiding multiple inappropriate referrals to specialist medical clinics.'

- * We would certainly agree that GPs can (and should) play an important role in helping the patient manage their illness, but the clear inference here is that the patients are not worthy of investigations in **medical** clinics?!

'To advise patients to maintain activity levels during 'setbacks'...'

- * *Not only is setback a wholly inadequate word, to maintain activity levels in the throes of infection and/or in relapse is not only physically impossible, but positively dangerous. This could not conceivably have been written by a medical professional with any personal experience or a genuine and in depth understanding of M.E.*

The associated 'evidence base'

Clearly the authors lean heavily on (their) interpretations of NICE & PACE. However, any objective analysis should convey that there is no evidence for the efficacy of any particular treatment (inc CBT & GET) for **severely affected** patients with M.E. In fact the authors of PACE themselves acknowledged the study was restricted to those with fatigue as a primary symptom and well enough to take part. Others such as Professor Derek Pheby are of the view that PACE cannot necessarily be translated to the 'wider' M.E. population.

As you are no doubt aware there are clearly more questions than answers with regard to PACE, not least methodology, outcome measures and missing/incomplete data highlighted in our own 'collaborative letter' with the MEA and Tymes Trust:

http://wmmeg.weebly.com/uploads/4/8/6/8/4868611/110518_-_pace_trial_letter_to_professor_white.pdf

And of course Professor Malcolm Hooper's own critique:

<http://www.meactionuk.org.uk/Normal-fatigue.htm>

To date 'answers' have been far from satisfactory and there is clearly an urgent need for a truly independent analysis to be carried out.

We look forward to hearing from you on both these interrelated and fundamentally important matters.

Yours Sincerely

Pauline, Jenny, Peter, Sue, Duncan and Jill

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