



# **Invest in ME Research**

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Professor Mark Baker  
Centre for Guidelines Director  
National Institute for Health and Care Excellence

## **NICE Guidelines for Myalgic Encephalomyelitis (ME)**

16 January 2018

Dear Professor Baker,

Thank you for your prompt reply on this matter.

You state in your reply that –

“the NICE guideline on ME/CFS was published before the PACE trial was seriously under way. Our recommendations were based on a body of research which preceded the PACE study. In our most recent review of the guideline, and cognisant of the controversies regarding the interpretation of the PACE results and methods, we assessed the evidence with, and without, the PACE results and the trial made no difference to the conclusions”.

As you will be aware Invest in ME Research challenged that.

It seems very strange that you can state categorically that NICE found no evidence to change the conclusions and, therefore, did not alter the recommendations of using CBT and GET for ME.

However, you are now aware that the NIH, CDC, AHRQ and IOM in USA are not only downgrading CBT and GET but have removed them from as recommendations.

Finland’s Valvira has also now removed the suggestion that CBT and GET be used for ME.

We have to state that we are somewhat shocked by your lack of action.

It is unfathomable why you continue to allow these recommendations for CBT and GET to stand.

The existing recommendations from NICE are hardly “a matter of concern to some patients and groups”!

They are, in fact, a matter of life and death for sick and vulnerable patients – those whom even you have admitted have been ill served by NICE guidance.

Perhaps it might be of use for you and your team to read the last post from Anne Örtégren – a brave, severely affected yet articulate patient in Sweden who suffered enormous damage caused, in part, by poor medical advice

<http://www.investinme.org/Anne%C3%96rt%C3%A9gren.shtml>

We wonder if this is the outcome you, and NICE, really wish to risk imposing on ME patients.



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To ignore completely the evidence that is in front of you makes you directly responsible for any harmful effects administered by practitioners of CBT and/or GET following referral by any doctor who follows NICE guidance.

Whilst you may be providing cover for establishment organisations and individuals, you are not protecting patients – surely that should be your overarching concern.

What you must do, at the minimum we feel, is to issue an addendum to the existing NICE guidelines which states that not only are patients wanting to remove the recommendations for use of CBT and GET for ME but also that the USA agencies have removed CBT and GET from their recommendations. This will not only give some protection for your own liability but you could actually be saving lives.

We also urge you to rethink your decision.

In the meantime we will advise all patients and their carers to retain a copy of your reply on their files so that, in the event of their being adversely affected by the NICE recommendation to use CBT and GET for ME, they may be able to use your statement to show the abrogation of responsibility by your organisation.

We would also state that this does not bode well for the forthcoming review of these flawed guidelines,

Yours Sincerely,

Kathleen McCall

Chairman Invest in ME Research  
and the Trustees of Invest in ME Research