



Charity number 1153730

# ***Invest in ME Research***

PO Box 561, Eastleigh SO50 0GQ, Hampshire, UK

**Tel: 02380 643736 07759 349743**

email: [info@investinme.org](mailto:info@investinme.org) web: [www.investinme.org](http://www.investinme.org)

---

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

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

18 January 2018

Dear Professor Baker,

Once again thank you for your reply. We do appreciate you taking time to reply and we do not wish to draw this out any longer than is necessary.

However, we have to say that neither will we let this rest whilst the consequences for people with ME are so serious.

Other organisations may passively follow the establishment methods and line that has so badly served patients over the last decades.  
We will not.

You will leave your position with NICE at some point soon and be replaced by another person who may not adopt your line of thinking or bring with them any sense of serving the patients and their families.

Therefore, it is imperative that we underline these points at this stage and it is why are using your time and ours to try to make these points.

As we stated previously, if you accept that you will fully replace the existing guidelines to improve the situation for people with ME then we really cannot understand why you cannot commit to either adding the addendum that we requested to remove both CBT and GET as recommendations for treating ME, or removing the existing guidelines already.

Stating that replacing the existing guidelines is a key component of the efforts to improve the situation for people with ME is welcome.

However, our request to remove the guidelines does not preclude you from taking any good points that may be present in the existing guidelines (such as the possibility for patients to decline any "treatment" offered if they do not believe it will help them – without being penalised by insurance companies or government departments, or the corporate parasites doing their work) and retaining them for new guidelines.

If, as you state, the existing recommendations are "carefully nuanced and crafted to give power and choice to patients" then why are you hearing of these awful stories from



patients who are on the receiving end of the treatments being forced on them due to NICE guidance?

Why is it that, during all the years since the existing guidelines have been operational, we have continually heard from patients and their carers of the deleterious effects of being having CBT and/or GET forced on them with the threat of benefits being removed?

The existing guidelines have done little to help doctors and done nothing to help patients – and the doctors themselves seem totally unaware of these “nuances” to which you refer.

You, yourself, admit that you have disturbing evidence of these treatments from patients about the “extent to which they are imposed on people who are unlikely to benefit from them”.

Yet even from the very time that the existing NICE guidelines were being drafted, as well as when they were issued, Invest in ME/Research has objected to CBT and GET being present.

NICE knew this long before the existing guidelines were issued. NICE were being told that CBT and GET were not applicable as treatments for ME during their development. [[1](#)]

This is a not new knowledge and ME patients even took NICE to a judicial review of the existing guidelines.

Therefore, it should be no surprise to hear of these stories from patients of how badly the recommendations of CBT and GET have affected their lives.

NICE chose to ignore patients’ voices for the existing guidelines both when they were drafted and when they were made operational.

We feel this may be occurring again now.

We do not believe that the problem lies in the unthinking and ill-informed manner in which the recommendations are imposed. We believe it is because doctors, who have little time for patients in general due to their heavy workloads, are presented with flawed recommendations by NICE and have no choice but to use them.

We have experienced this ourselves and all patients know of this.

The problem lies with NICE and the heavily BPS-influenced guidelines that were created – against patients’ wishes.

We do not believe clarification is needed in this context.

We believe CBT and GET need to be removed now.

You state that scrapping existing guidelines would be “massively counter-productive as it would almost certainly result in the withdrawal of the already dwindling number of services available to people with ME”.

We doubt that. In fact, we totally disagree with that assessment.

There are indeed few services for ME (due to decisions and policies of UK governments, MRC, NICE, Chief Medical Officers and certain royal colleges and individuals within them) but those that do exist have been based almost entirely on flawed CBT/GET clinics that were set up, again against patient voices, to continue to offer these flawed treatments.

We know that doctors feel constrained by the NICE guidelines and the recommendations of CBT and GET and they feel unable to offer more.

Removing the existing recommendations for CBT and GET, or removing the existing “unsatisfactory” (your words) guidelines completely would leave the doctor able to offer more flexibility in performing tests, in looking for treatments, in appraising themselves of research and generally treating the patients as human beings with a health problem to resolve.

It would also improve the situation for patients – immediately – as no self-serving insurance company could force CBT and GET on to patients before paying deserved benefits, using the excuse that NICE have recommended these flawed treatments.

You would, in fact, be performing a huge favour for ME patients by removing the existing guidelines.

It would also send out the message, loudly and clearly, that patients have been ill served by existing guidelines and recommendations and that you are indeed now going to focus efforts on relevant and effective guidelines that benefit patients.

It would send a signal to those establishment organisations and individuals who have benefited from the continued prescribing of CBT and GET that the game is up.



Add the addendum to remove recommendations for CBT and GET or remove the existing guidelines now – it is the only logical course of action that can be taken if the welfare of patients is really the prime objective.

You (and NICE) will gain enormous respect from the patient community by taking this bold action.

In addition, let us make one point – and we wish to stress this.

You cannot remove GET and yet still retain CBT as a recommendation.

Both of these recommendations must be removed.

By retaining CBT as a recommendation then this only helps those organisations and individuals who continue to promote biopsychosocial theories about ME for their own vested interests and will continue the threat to the welfare of ME patients.

CBT in the existing NICE guidelines is tightly connected to GET as it asserts that fear of exercise and false illness beliefs perpetuate the condition.

CBT and GET are the two major components causing the damage being done to people with ME. Their continued use affects everything. We do not accept that “in particular” GET is not acceptable.

CBT **must be removed also** in parallel with GET.

By leaving CBT as a recommendation, you will leave the door open for continued funding of the same bogus research that has monopolised and compromised the lives of people with ME and their families for so long.

It is unacceptable.

We are telling you directly that leaving both CBT and GET as recommendations in existing (or future) guidelines will damage the health of people with ME.

If the treatments mentioned (CBT and GET) are already accepted to be “inappropriate”, “unacceptable” or “unsuitable” as recommended by existing the guidelines then your (and NICE’s) duty and obligation to sick and vulnerable patients is to remove them immediately.

There is no other logical course to take.



From your letters we accept that you are sincere in your intent to modify guidelines for the benefit of patients.

Yet there just simply is no excuse to retain CBT and GET.

Please do not let this opportunity pass to help the current situation for ME patients, before you move on to another position.

Leaving the current recommendations for CBT and GET in place for another two year whilst a new set of guidelines are developed would be negligent.

This is something you can do now for ME patients that will have benefits for the whole ME community - immediately.

Perhaps no single act in current times could be seen as better serving the health of a large section of the population (which surely is NICE's remit) than acceding to our request to add an addendum to the existing guidelines to revoke the recommendations for CBT and GET, or to remove the existing guidelines completely.

We thank you again for your time in receiving and reading our letters.

We assure you that our only motives are concerned with the welfare and the future of people with ME and their families,

Yours Sincerely,

Kathleen McCall

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

## **References:**

1 <http://www.investinme.org/iime%20campaigning-nice-guidelines%20iime%20response.shtml>