



Charity number 1153730

# ***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)**

10 February 2018

Dear Professor Baker,

Thank you again for the time given to reply to our email.

We understand that you now wish to halt further communication on the issues that we have raised and move all discussions under the umbrella and scope of your planned workshops for a full replacement of the existing guidelines – which you have indicated will be “torn up”.

We do not expect you to reply to this – but we do feel it worthwhile for all patients and for the NICE comms to see our summary of the points coming from your emails and, subsequently, the likely effect on the two-year period that the review will use and which may or may not result in improvements for patients.

We include that summary below.

Thank you again for taking the time to reply.

We hope that the comments and proposals we have made will be acted upon by NICE immediately and not wait until one of the planned workshops, or wait for more harm to be done to patients.

NICE must serve the needs of patients.

Unfortunately, we fear that NICE will not do as we suggest and will not act for the interests of patients.

We hope that you prove us wrong.

We wish you well in whatever undertaking you pursue post-NICE - and perhaps will reflect on the effects that NICE decisions have on a population of very ill patients who have been so poorly served by establishment organisations in the past,

Yours Sincerely,

Kathleen McCall

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



## **SUMMARY**

✚ Professor Baker believes withdrawal of the guidelines would result in the entire support structure being removed. He has said that the services that are now provided to patients will be withdrawn if the existing guidelines are withdrawn immediately.

- ◇ We have said we disagree with that.
- ◇ The reality is that the services offered currently are sparse at best and detrimental to patients' health at worst and rarely meet the needs of patients.
- ◇ It must surely be recognised that, in fact, there is a distinct lack of services for ME patients, then we do really think it again illogical to worry about services disappearing.
- ◇ As all doctors will be told that a new set of guidelines will appear then new services will result from that.
- ◇ CCGs still have a responsibility to patients.
- ◇ In addition, we have suggested that NICE have a choice of action – if NICE does not wish to remove the existing guidelines then just add the addendum that CBT and GET are no longer valid recommendations.

The extremely poor or inappropriate services currently offered should not be a reason to retain flawed guidelines that harm patients.

✚ Professor Baker states that "the actions of some service agencies (health care commissioners, children's services, schools and benefits agency amongst others)"...."is not something which NICE has direct influence over".

- ◇ Yet NICE also seem to be saying that NICE guidelines are responsible for services being provided because they will disappear without them – yet at the same time claiming that NICE has no direct influence over those services using them. It is hard to follow this reasoning.
- ◇ The actions of some service agencies (health care commissioners, children's services, schools and benefits agency amongst others) are the direct result of the NICE guidelines and the recommendations therein and NICE must be held accountable and take responsibility. How it is felt appropriate for NICE to abrogate its responsibility is very odd – NICE has been told by Invest in ME that the recommendations in the guidelines were inappropriate for ME at the time that the existing guidelines were being developed.



- ✚ Despite admitting the unpopularity of the guidelines with patients, which Professor Baker and NICE "clearly now empathise with", Professor Baker states that the majority view has been that they have done some good.

- ◇ The guidelines must surely be created to benefit patients.

Professor Baker admits that they are unpopular with patients.  
Yet patients are only offered empathy - not action.

To what majority view is Professor Baker referring?  
Is the majority view that of doctors? We doubt it!  
Is the majority view that of the psychiatrists who have so dominated the debate regarding what guidelines are imposed on people with ME, and what research is to be funded?  
This seems a very odd conclusion in the circumstances.

Mere words being thrown around without any substantiation or detail is not just careless - in this situation it is disingenuous and maybe even dishonest.

If Professor Baker and NICE state that a majority view supports the retention of the existing guidelines then they must provide details of whom that majority consists of. For it is not amongst patients.

- ✚ Professor Baker believes that the guidelines legitimise the diagnosis.

- ◇ Yet how could that be when few services have been offered, when the services that are offered are inappropriate and when Professor Baker acknowledges the horror stories confronting him where patients are not treated seriously?

How can it be when the diagnosis of ME is still an almighty mess?

In short, we contend that the NICE guidelines have done nothing to legitimise the disease.

In fact, they have maintained an ignorance of the disease and allowed patients to be harmed - and continue to allow patients to be harmed.

Legitimation is not what patients feel.

We also contend that doctors have been ill served by these existing guidelines and cannot help their patients.

Patients do not feel legitimised.

After two or three decades of seeing this disease mishandled and starved of funding for proper research then we can attest to the fact that it has been far from legitimised.



Even the main protagonists of the BPS ideology, an ideology that has so completely raped this illness with its misinformation and vested interests, have stated that they do not see ME as being a disease – but instead a behavioural illness that can be cured by quack treatments.

The existing NICE guidelines have done nothing to legitimise or help ME patients and the services that are on offer are mostly inappropriate or sparse – influenced totally by the existing NICE guidelines.

✚ Professor Baker has stated that the existing guidance is carefully worded with the implication that doctors are somehow not only aware of the nuances but are also understanding them.

◇ We have to disagree.

If NICE recommend CBT and GET and if these therapies harm patients then no amount of crafted wordsmanship in the world will avoid the situation where patients are harmed.

◇ We have stated that the “nuances” and “craftsmanship” of the wording in the existing NICE guidelines to which Professor Baker refers are lost on doctors, and on almost everyone except NICE.

✚ Professor Baker states that the (existing) guidance is very carefully worded to protect patients and are “deeply concerned” at the actions of some service agencies (health care commissioners, children’s services, schools and benefits agency amongst others) which clearly do not represent the wording and intentions of the guidance.

Professor Baker then states that this is not something which NICE has direct influence over and can only suggest that we direct our ire on those responsible for irrational decisions and the misquoting of our guidance.

◇ This is an astonishing statement to make - and far from true.  
Of course NICE directly influences what doctors prescribe.  
Absolutely NICE has direct influence.

It is NICE who are responsible for the recommendations which doctors are compelled to take into account.

This statement demonstrates that NICE still really has no idea at how much damage these existing guidelines have done, and no idea of what damage they continue to do.

✚ Professor Baker suggested that we direct our ire on those responsible for irrational decisions and the misquoting of our guidance.



- ◇ Our "ire" is actually directed at those responsible for irrational decisions or decisions that make ME patients worse.

Professor Baker admitted that the guidelines will be replaced entirely.

Professor Baker has agreed that CBT and GET are perceived and experienced by patients as harmful

We believe that Professor Baker accepts the claims that patients have been harmed by CBT and GET

It therefore defies logic to retain harmful recommendations for two more years or more- when it is clearly understood that patients are being harmed by these recommendations.

- ✚ Professor Baker stated that the PACE Trial has had no effect on the recommendations of NICE (despite last summer the surveillance review quoting the PACE Trial).

- ◇ In our letter to Professor Baker we did not refer to PACE as being the base of evidence for NICE guidelines.

We only intended to refer to PACE in case Professor Baker came back to us to deflect our argument that CBT and GET need to be dropped by referring to PACE.

- ◇ Yet NICE did use it to base its decisions in the surveillance review of 2017

- We have stated it is illogical, and harmful to patients, that NICE retain the existing guidelines when it is admitted that they are not fit for purpose, are not what patients want and will be discarded in any case.
- We have stated that there is no rational reason to maintain the existing guidelines if they do harm and that, at the very least, NICE must follow what USA have done and remove recommendations for using CBT and GET as treatments for ME with an addendum to the existing guidelines.
- We have requested that this addendum for removing recommendations for CBT and GET is communicated to other healthcare agencies around the world who have misguidedly used the existing NICE guidelines as any basis for their own treatment of ME patients.



- We began this series of letters to Professor Baker due to the comments attributed to him and NICE. These comments have made us wonder how these would be translated into action.
- Professor Baker's reply to us – a few hours before the stakeholder meeting – clearly seemed to be contradictory to the comments that Professor Baker made to the participants in the stakeholder meeting and raised major concerns for us as to the actual way NICE were intending to proceed.
- This, and further replies to our initial request to remove CBT and GET from existing guidelines, baffled us.
- The fact that Professor Baker has stated that the existing NICE guidelines will be torn up indicates this realisation that NICE and the existing guidelines have failed.
- What patients have said has proven to be true. Yet NICE did not listen.
- We detect even now that these messages still have not been taken on board.
- Comments such as "we will tear up" the existing guidelines need to be translated into immediate action.
- We have words from NICE - but no action.
- NICE must separate the decision on the continuation of the existing guidelines from the review of them.

These are two separate matters – linked by the fact that NICE has already decided to tear up the existing guidelines and that Professor Baker accepts that CBT and GET are harmful to ME patients.

- The existing guidelines must be withdrawn or NICE must add an addendum that CBT and GET are no longer recommendations.
- The refusal to add an addendum to existing guidelines to remove **BOTH** CBT and GET is illogical in the context of the remarks made by Professor Baker/NICE.



- The refusal to withdraw the full guidelines whilst they are torn up and new guidelines developed also carries a level of illogical reasoning.
- Professor Baker has
  - admitted the existing guidelines are unfit,
  - he has accepted the horror stories of patients being coerced into trying CBT and GET and being harmed by them,
  - he has heard of insurance companies denying benefits when people refuse to agree to try these flawed theories recommended by NICE.

In all of this how can it be logical, or moral, or safe, to retain these existing guidelines, and especially the disastrous and damaging recommendations for CBT and GET?

If one takes an example.

If a drug is recommended by NICE for a disease and some time later the drug is found to be harming patients then surely NICE would take steps to remove that drug.

They would not retain it as a recommendation, to be in use for two years whilst they developed a new guideline for the disease.

To avoid further harm to patients they would remove the drug immediately.

- This is the same situation that NICE now face with CBT and GET for ME.
- Professor Baker has written to IiMER that he

“will discuss at the highest level at NICE what remedial action to help patients we can take in the meantime.”

We hope that this will result in issuing the addendum to the existing guidelines that removes CBT and GET as recommendations for ME – or otherwise the withdrawal of the existing NICE guidelines for ME immediately.

- We do not share the euphoric tributes to NICE for arranging a workshop where the audience is told everything that they want to hear.

We do not feel we have that luxury.

- Years of experience of establishment tactics involving wasting several years on initiatives that are already designed to deliver nothing of value (MRC “expert” panels, cmrc, NICE, mega, etc.) have made us wary of the corrupt systems in place.
- Based on their track record NICE do not yet deserve any such trust.



- ME patients have had very little bargaining power over the last decades thanks to the insidious and immoral network of BPS protagonists who have influenced all policies on ME in the UK and taken over decision making in weak and apathetic research councils and government departments.
- What patients have been able to retain is the ability to give or withhold their trust in new initiatives that promise change to improve their lives. In the world of social media, where the playing field has been levelled in recent times and allowed patients to challenge biased research, this provision of trust by the patient community can be a useful commodity.
- We therefore do not give NICE our trust.
- Our recommendation to ME patients and their families is not to trust comments by NICE and not to trust NICE at all – until the day arrives that NICE actually deliver and operationalise guidelines for ME that really do reflect the reality and needs of ME patients and their families.
- Currently that date would be somewhere in two years time.
- NICE can bring forward that date by acceding to our request to add an addendum immediately to the existing guidelines to remove recommendations for BOTH CBT and GET - or by withdrawing the existing guidelines for ME immediately, and issuing a press release to doctors in UK and abroad that NICE has found the existing guidelines to be unsatisfactory, that they are going to be torn up and completely revised.
- If NICE do this then trust will surely be given by ME patients.
- Sir Andrew Dillon might even find it within himself, on behalf of NICE, to issue an apology to ME patients for the wasted years and the distress and the harm which the existing guideline recommendations have caused.
- If NICE do not take this eminently logical and fair decision immediately then there is no reason to give that trust.





- We really do hope that NICE now act in a logical and fair way with the patients in mind - uninfluenced by the evil of the BPS network that has been allowed to flourish over the last decades.

## **Add the addendum to remove CBT and GET – or TearIt Up!**

**Now!**

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- Finally, look at a communication below, from a patient, that has come to Invest in ME Research in the last month - a letter which neatly describes the appalling consequences of recommending CBT and GET - something for which Professor Baker and NICE cannot pass on responsibility to others.

This is the result of NICE's recommendations in their existing guidelines - and this just underlines everything we have been trying to make Professor Baker, and NICE, understand.

### **To Invest in ME Research**

I have been closely following the continuing correspondence in relation to the call for revision of the NICE guidelines.

In particular the removal of CBT/GET.

I have had M.E. for almost four years and am quite severely affected.

I am housebound most of the time and often bedbound.

I was previously a 'high flyer' (my neurologists' words) and a civil servant with a social work background.

Due to my illness I am no longer able to work, and have just been through the very painful process of applying for ill health retirement.

My pension provider (through the *(name provided)* pension scheme) has a two tier system for pension awards in the circumstance of ill health retirement.



I have undergone five medical assessments during the process and have been assessed as permanently incapacitated in terms of employment.

However, as I have not completed the treatment, as recommended in the NICE guidelines, I cannot obtain the higher rate pension.

The treatment namely being CBT and GET.

I have engaged with the specialist M.E. service in (*location provided*) but was unable to continue as attending sessions made me more unwell.

I tried CBT through my local mental health service, attending three out of six sessions, this made me more unwell and put me back into bed for weeks.

I am in receipt of the highest rate of both ESA and PIPS.

These were both awarded following the first medical assessment, which I understand is not the position for far too many M.E. sufferers.

I have taken my ill health retirement case to appeal within my pension service.

The position of the original decision not to award me the higher rate pension has been upheld on the grounds that I have not completed CBT and GET.

My pension provider will now escalate my appeal to stage two of the process.

However, the decision makes it clear that, in order to succeed, I need to prove that I have completed CBT and GET.

I am faced with a position that is unfair and takes away any right I have not to undergo treatment that exacerbates my illness.

I have had support from my union (*name provided*), however they aren't familiar with the fight that M.E. suffers like myself face.

I have previously had a life where i travelled up and down the country for my career, helping to make a difference in the lives of vulnerable children. I had authority and was very much a professional. I have always worked within the public sector, both local and central government. I had a lively social life, always on the go with my partner and family.

Now my life revolves around my bedroom. I rely on pillows, blackout curtains and strong medication to try and control my pain. If I journey out, it is to visit my G.P. which takes around three hours to get me ready for, with lots and lots of assistance from my wife, who is also my carer and carer to our 18 year old disabled son.



I often find it difficult to construct challenges around my illness as i simply can't find the words due to my diminished cognitive functioning. This is one of the hardest symptoms to deal with. The loss of intellect. It's in there somewhere, I'm in there somewhere, but I just can't get the words to make sense.

It is imperative that someone listens to our voices and I am so thankful for your determination in challenging the medical profession around our treatment options.

It will probably be too late to make any difference to my case.

I hope that in the future no one will be penalised for not undergoing treatment that is harmful to their health as a result of your campaigning; that CBT and GET will be removed from the guidelines with immediate effect, rather than waiting for years while the guidelines are revised.

Please please continue the fight for those of us struggling to do it for ourselves

- Little more needs to be said.

This letter alone is a testament to the failure of NICE to help people with ME and their families - and a decade on from the creation of the existing guidelines there is enough of an indication that no lessons have been learnt - or any real intent is underway to correct the failings.

- Throughout our correspondence it seems clear that Professor Baker is oblivious to the elephant in the NICE room - no matter how much damage it is doing to patients.

We can only surmise that more influential forces are still present, continuing to force more CBT and GET on to patients.

If that were so it would be shameful.

CBT and GET must be removed from the existing guidelines now.

NICE, and those deciding on the future for people with ME, must be held accountable if more people are harmed by retaining the existing damaging recommendations for using CBT and GET for another two or more years.