Invest in ME Research Statement
NICE GUIDELINES
TAKING US FORWARD TO 2007

29 October 2021

The National Institute for Health and Care Excellence (NICE) has today (29 October 2021) released a statement [1] to announce the publication of the new updated guideline on the diagnosis and management of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Now designated **ng206,** the guidelines document [2] of 2021 replaces the flawed NICE guidelines published in 2007 (CG53) [3].

It would be easy to create a few popular soundbites and make positive noises about these guidelines and how they will change the lives of people with ME. Yet it may be more prudent to add realism to the discussion – based on experiences from years of consistent campaigning to build a better future for those affected by this disease.

The Process

Publication of the guidelines follows several years of discussions by a "*balanced*" (NICE's words [4]) working group, the expenditure of many hundreds of thousands of pounds of public money, a review period undertaken whereby all stakeholders could comment on the draft guidelines, and three separate publication dates being set by NICE before the final version of the guidelines documents are released to the public today.

Yet the guidelines process will be remembered more for the period of confusion, secrecy and miscommunication that followed the irregular pause in publication of the guidelines that was instigated by NICE on 17 August 2021 [5], supposedly due to "concerns" by some establishment organisations.

Then followed months of secret discussions with preferred groups, breaches of NICE's guidelines development rules and regulations, perceived caving in to pressure from some establishment influences, and selection of a minority of compliant "patient representative groups" to attend an illicit roundtable meeting.

All held away from any scrutiny by the vast majority of registered stakeholders and from all people with ME and their families.

The roundtable meeting had no credible meaning, was constructed with little adherence to any acceptable due process and yet partially legitimised by some self-serving organisations who claimed to want the guidelines published immediately on the one hand while sanctioning the pause in publication by happily participating in the roundtable on the other.
Predictably, the roundtable achieved nothing of consequence.

Yet it was the finale to a guidelines development process that had turned into a debacle with mistrust brought on by the lack of transparency shown by NICE and by external influences causing anxiety and despair amongst patients.
A debacle for what should have been an honest, open and significant process that could have removed the blight on the lives of people with ME caused by the last fourteen years of flawed guidelines being propped up by an out of date mentality in the UK.

We described this period as a veritable omnishambles [6].

This is not what one should expect from a publicly funded organisation - especially one that continues to exert so much influence on patients' lives.

NICE
The NICE press release contains the same disingenuous spin that has characterised their activities since 17 August.

The claim by NICE today that they "*know that people with ME/CFS have had difficulty in getting their illness acknowledged*" is a disgraceful deceit from an organisation that has maintained a flawed set of guidelines for fourteen years with little concern for the "*difficulty*" faced by people with ME and their families.

In communications with NICE guidelines directors IiMER requested that the dangerous recommendations for CBT and GET were removed from the 2007 guidelines whilst the guidelines review was underway due to the harm that they were doing and had done [7, 8].
NICE declined.

The existing guidelines and their harmful recommendations have been left in place for fourteen years causing untold damage to patients – not just in the UK but also in countries that have mistakenly adopted the NICE guidelines as some sort of "gold standard".

NICE is an organisation that has had no scrutiny of its operation and seems unaccountable to anyone for its poor performance.

The Guidelines

So to the updated guidelines.

When a national organisation that has been given responsibility for clinical excellence and care announces that a new set of guidelines for a disease is to be created, following fourteen years having passed since the last version was published, then it might be considered to present a great opportunity.
Indeed, Invest in ME Research had campaigned for, and welcomed the review.

Here was an opportunity to evaluate new research, to document and recommend new treatments and practices, and to introduce new recommendations and guidance in order to remove flaws in the previous outdated guidelines.
After all, new research into the disease would inevitably have taken place during those fourteen years that would necessitate modification, and effective treatments may well have become available.

It is a damning indictment of the state of affairs regarding ME in the UK that the updated NICE guidelines can do no such thing.

Instead, the guidelines document of 2021 is only able to attempt to undo the damage done by inaction, ignorance, apathy and negligence during the past 14 years.

The 2021 document stands as a testament to fourteen years of nothing much changing for people with ME, fourteen years of failure from governments and establishment healthcare and research organisations in treating this disease.

It is disappointing, though not surprising, that it took so long to accept what some organisations such as Invest in ME Research have consistently said - that there is no reliable evidence that Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET) show any benefit whatsoever for ME/CFS patients.
Quite the contrary.

These new guidelines should have gone further and removed ALL lengthy discussion on physical activity and a “new type of CBT” rather than retain one flawed area of the 2007 guidelines and trying to justify its retention by saying it is personalised and to be offered to those who ask for it.

Despite no good evidence to justify CBT NICE decides that it wishes to keep it for those who want it...What sort of guidance is that?!
Either they have evidence or they do not.

There will be plenty of work for those healthcare professionals involved in ME/CFS in correctly diagnosing and monitoring patients as well as helping out with aids and benefits instead of trying work out how to offer personalised physical activity and CBT.
The guideline should have stood by its evidence findings to allow a completely fresh start. Instead, we have a fudge and new terms such as 'person centred energy management' appearing. We wonder how that will be implemented.

The charity strongly objects to the ridiculous special mention of the Lightning Process, a trademark [pyramid] business in these ME/CFS guidelines.
There is absolutely no point in giving any publicity to a process that caused a reprimand to be issued by the Advertising Standards Authority for making unsubstantiated claims.
The "Do not offer" statement should apply to all alternative therapies – or should not even be in this document.

The main guidelines document now contains some common sense approaches to treating ME/CFS patients and the acceptance that patients are able to refuse any "therapy" (with the implication that they should not suffer consequences from insurance companies).
However, there remain major question marks on how resource will become available to retrain healthcare staff – both with regard to the disease and with regard to prejudiced views of the disease that have been allowed to be maintained for so long by the lack of action from governments, research councils, chief medical officers and institutes of national healthcare – and NICE.

These updated guidelines should not be afforded unequivocal support simply because one deleterious recommendation for treatment from the flawed 2007 guidelines is removed and an impression is given of watering down another.
Rather patients and carers should feel aggrieved and angry that nothing has changed in fourteen years for those who have this disease.

One needs to view the 2021 guidelines in the context of what preceded them and remembering all of the harm that has been caused since 2007.

People with ME should expect that their illness would be taken seriously by the medical profession as the neurological disease that the WHO recognises and that research would be properly funded to facilitate early diagnosis, effective treatment and, hopefully, cure(s).
That has patently not occurred in the past decades.

The 2021 guidelines could have been written in 2007, such has been the lack of progress. In fact, had NICE listened to patients then and provided the 2021 guidelines in 2007 then much of the ignorance, stigma, clinician-patient antagonism, severe harm to and possibly even deaths of people with ME could have been avoided.

Instead, people with ME have had to live with this dystopian healthcare provision in the UK.
They have had to endure establishment games for 14 years since the previous 2007 guidelines for ME were published. Fourteen years of the harm caused by flawed NICE guidelines, fourteen years and more of the MRC's god-forsaken "expert" panels and barren and disingenuous 'collaboratives', fourteen years of UK CMO ignorance and apathy, and decades of entrenched views among royal colleges and institutes which had no basis in reality but managed to support the careers of some.
It must not continue.

Far from being the gold standard for guidelines for other countries, we would suggest that agencies developing guidelines in other parts of Europe should consider their own path and not blindly follow a UK organisation that has twice been taken to, or threatened with, a judicial review - by patients!

The 2007 NICE guidelines are there as the epitaph to the failure of NICE, the MRC, the UK CMOs, royal colleges and the government.

The 2021 NICE guidelines document shows how bare the landscape has been, and still is for people with ME in the UK.

Fourteen years with little progress.
An appalling legacy for those who have been in positions of influence and responsibility over the past decades.

Perhaps the acceptance that the UK healthcare has failed patients for fourteen years should now be a call to action to treat ME with the urgency and the resource that has rapidly been made available to treat long covid.
NICE might begin that call by issuing a formal apology for their part in the misery of the lived experience of people with ME over the past fourteen years!

So now we start again - from the position that we were in in 2007.
The development and publication phases of an updated set of guidelines have finally been completed.
Now a new phase is entered – implementation.

Though we saw nothing of great accomplishment in the final guidelines (we commented fully in our response to the draft guidelines [9]) the 2021 version may, nevertheless, allow a start in resetting the environment to reflect a more realistic picture of the disease.

Time will tell if real change occurs. Nothing can be taken for granted and the history of ME dictates that caution and vigilance would be the best approach as nothing is certain.
As we commented in the ***The Status of Research, Treatment and Perception of Myalgic Encephalomyelitis (ME) in UK*** report of 2018 [10] –

> "In 2007 Invest in ME Research issued a status review of these recommendations from the Chief Medical Officer's Report.
> None of the recommendations had been implemented at that time.
>
> In 2018 we revisited the CMO report and the recommendations from 2002 and it is clear that still none of the recommendations have been implemented."

The future for people with ME still, tragically, remains uncertain following the publication of these guidelines – and lies in the hands of others and their interpretation of these guidelines.

The Chair and Board of Invest in ME Research

October 2021

References:

1. NICE statement 29 October 2021
2. ng206 the guidelines document
3. NICE Guidelines published in 2007 (CG53)
4. NICE Guidelines Development - Turning a farce into a shambles
5. Letter to NICE Management Regarding Pause of Guidelines Publication
6. NICE Guidelines Development 2021 - Legitimising the Omnishambles II
7. IiMER Correspondence with NICE Guidelines Director Professor Mark Baker
8. IiMER Repeated Request to NICE-Remove CBT/GET as recommendations
9. IiMER Response to Draft Guidelines 2020-2021
10. The Status of Research, Treatment and Perception of Myalgic Encephalomyelitis (ME) in UK 2018

Invest in ME Research
UK Registered Charity Nr. 1153730

www.investinme.org