



Invest in ME Research

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Charity number 1153730

Dr Paul Chrisp, Director of the Centre for Guidelines
Professor Gillian Leng CBE, Chief Executive, NICE

Cc:

Sir Ed Davey MP, Leader of the Liberal Democrats

Mr Jonathan Ashworth MP, Shadow Secretary of State for Health and Social Care

Mr Sajid Javid MP, Secretary of State for Health and Social Care

20 August 2021

NICE pauses publication of updated guideline on diagnosis and management of ME/CFS

Dear Dr Chrisp and Professor Leng,

Invest in ME Research is a UK charity that funds and facilitates biomedical research into myalgic encephalomyelitis (ME or ME/CFS). The charity is a stakeholder in the development of guidelines for ME.

We write to you regarding the recent decision by NICE to pause publication of new guidelines for ME— a decision taken hours before the preset (second) agreed date for publication, and regarding your continuing woeful lack of consideration for the welfare of people with ME and their families.

On 17th August NICE published a statement whereby it informed stakeholders that the NICE guidelines for ME (CG869) would be paused. [1]

Your press release carried the statement –

“we have not been able to produce a guideline that is supported by all.”

This is irrelevant.

It was the decision unanimously adopted by the working group that NICE set up to publish the final guidelines.

This is why there was a review.

Due to the NICE decisions to “balance” the working group instead of using unbiased professionals (as we warned in our article [2]) then there was always likely to be the case where one “side” disagreed.

This was of your own making.



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In 2007 when NICE published guidelines for ME (CG53) there was disagreement. Patients objected to having CBT and GET forced upon them when they knew that they did harm.

So great was the opposition to the 2007 NICE guidelines that NICE were taken to a judicial review – by patients – a case that was only lost due to machinations behind the scenes by NICE and its legal team.

Yet despite the patient objections NICE decided to publish anyway.

Therefore, a precedent was set to continue to publish despite one party disagreeing.

NICE eventually was forced to concede that a review of the 2007 guidelines was required (after a decade of lobbying by Invest in ME Research and our supporters).

A review was carried out.

Draft guidelines were published in 2020.

Comments to the draft guidelines were received.

A date was agreed to publish the guidelines in April 2021.

That date was changed and 18th August was decided for the final guidelines to be published.

Now NICE renege on that decision by caving in to pressure from establishment entities that have never served people with ME and continue to inflict damage on this patient community.

Having analysed the draft and the final guidelines Invest in ME Research were not at all overjoyed at the final outcome and would already state that it carries flaws.

Yet we submitted our concerns to NICE via the due process and have abided by the process where these comments are evaluated [3].

In the press release issued by NICE it was stated -

“unless the recommendations in the guideline are supported and implemented by professionals and the NHS, people with ME/CFS may not get the care and help they need.”

Invest in ME Research contend that patients have never been receiving care and help during the fourteen years since the CG53 were published in 2007 so the question would be - What is different?

It should be noted that Invest in ME Research repeatedly commented in our submission to NICE regarding the draft guidelines on the need for retraining and the lack of specialist teams and the likely requirement for more resource in order to effect the changes – despite NICE claiming repeatedly that no extra costs or resource would likely be incurred or required.

Our concerns were dismissed.

Of course, we know why some “professionals” and career figures object – removing GET would make it more difficult to force these same deleterious treatments on to long covid patients, thus affecting establishment careers! Moreover, the gravy train for establishment figures would be lost if CBT and GET were dropped as recommendations for ME from NICE.



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However, the latest actions of NICE demonstrate yet again that it is an organisation that does not have the welfare of patients as their prime concern and its policies are obviously being controlled and manipulated by others in the background – without any transparency. This leads us to the view that we are witnessing gross incompetence and wilful negligence from NICE.

What must be done to make you realise that during and since the 2007 CG53 guidelines were developed and finally published in 2007 you have poorly served the ME patient community?

You are, in fact, playing with people's lives.

This is unacceptable and we now invite support from organisations and leaders from outside the sphere of influence of NICE and its establishment cronies to ensure that this does not stand.

What you are doing affects people with ME and their families who have already endured countless years of prejudice, ill treatment, ignorant clinicians and appalling manipulation by establishment groups that represent no one but themselves.

By pausing the 2021 guidelines in this way and acquiescing to pressure from those who have already caused harm to patients then we believe that you have breached your own regulations in developing guidelines.

We believe you are also infringing human rights.

What you must do now is to publish these 2021 guidelines as was intended, warts and all.

A post-publication review then needs to be carried out to assess the effectiveness of these guidelines.

If you fail to do this immediately then you must add the addendum to the existing 2007 guidelines that warns of the damaging consequences to patients of CBT and GET, as requested to Professor Mark Baker (former director for NICE guidelines) [\[4\]](#).

There must also be an inquiry into NICE to determine its independence, its role and remit for continuing to create guidelines and an inquiry into who is actually controlling NICE's agenda with regard to ME.

Professor Leng – on your NICE bio it states –

“she.....developed into a passion for using evidence to improve care”

The CG869 clearly shows there is no good evidence for CBT and GET and therefore little credence for attempts to thwart the removal of these deleterious treatments for ME.



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It also states -

“Her aim is to transform the organisation with new methods and processes to put NICE at the forefront of evaluating new medicines, devices and diagnostics, and deliver dynamic, living guidelines.”

We request that you live up to these aims.

The 2007 guidelines failed patients.

The 2021 guidelines would merely have put us back to where we were before the flawed 2007 guidelines were published.

However, at least they would have, in part, avoided the continuation of deleterious recommendations for treatments that patients do not want or need.

As we have said many times, better no guidelines at all than to have guidelines that harm patients, or even kill them.

We await your urgent attention to this matter.

Yours Sincerely,

Kathleen McCall
Chairman Invest in ME Research

References:

- 1 NICE press release 17th August 2021
<https://www.nice.org.uk/news/article/nice-pauses-publication-of-updated-guideline-on-diagnosis-and-management-of-me-cfs>
- 2 NICE Guidelines Development - Turning a farce into a shambles
A Continuing Saga of Ineptitude
<https://www.investinme.org/IIMER-Newslet-1810-02.shtml>
- 3 Invest in ME Research Response to Myalgic encephalomyelitis/chronic fatigue syndrome: diagnosis and management CG869
<https://www.investinme.org/IIMER-Newslet-20-12102.shtml>
- 4 Correspondence with Professor Mark Baker, Director NICE Guidelines Development – 2018
<https://www.investinme.org/IIMER-Newslet-1801-01.shtml>