



Invest in ME Research

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Charity number 1153730

Dr Paul Chrisp
Director of the Centre for Guidelines at NICE
National Institute for Health and Care Excellence

NICE Guidelines for Myalgic Encephalomyelitis (ME)

16 November 2020

Dear Dr Chrisp,

Invest in ME Research is a UK charity (charity nr 1153730) that seeks to educate and campaigns for biomedical research into myalgic encephalomyelitis (ME). The charity also facilitates and funds biomedical research into ME.

Invest in ME Research is a stakeholder in the NICE Guidelines review process for ME, and is currently reviewing the recently published draft guidelines [1].

However, we feel there is an urgent matter that needs to be addressed immediately. This concerns the continuing recommendation for use of Graded Exercise Therapy (GET) for ME that is currently retained in the current NICE Guidelines for ME (CG53) and still standing as a recommendation for doctors treating people with ME.

In correspondence with Professor Mark Baker (NICE Guidelines Director) in 2018 [2] we had requested that NICE remove the recommendations for CBT and GET immediately from the existing guidelines due to the deleterious effects on people with ME.

In our correspondence, Professor Baker agreed that GET was perceived and experienced by patients as harmful and we believe that Professor Baker accepted the claims that patients have been harmed by GET.

Professor Baker declined our request to remove GET at that time but responded –

“I appreciate that the existing recommendations are a matter of concern to some patients and groups and we will give some consideration to whether we need to modify or omit any of the existing recommendations during the development of the new guideline.”

Well, now the development of the new guideline has reported that GET should no longer be used as a recommended treatment of ME.

Therefore, there is no excuse to retain GET as a recommendation when nobody wants it, including your guidelines review team.

There is no longer any argument for delaying an immediate removal of GET from the current guidelines and informing all GPs and healthcare providers that GET should not be recommended for ME.



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As we suggested to Professor Baker this can be achieved via an addendum to the existing guidelines and via the routine warning system that NICE employs, via your web site and social media (as you have done for Covid-19 [3]).

The final version of the guidelines for ME will only be published in April next year and we feel that it would be negligent to leave a dangerous recommendation in place for yet another six months.

NICE ought to be accountable for any damages, and costs, relating to the burden and harm brought on to patients by retaining this erroneous and negligent recommendation for a moment longer than necessary.

We hope that you will decide to take action on this urgent matter.

Thank you for taking the time to consider this request,

Yours Sincerely,

Kathleen McCall

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

- 1 Guideline Myalgic encephalomyelitis/chronic fatigue syndrome: diagnosis and management Draft for consultation, November 2020
<https://tinyurl.com/y3vxfkwj>
- 2 Letters to Professor Mark Baker at NICE
<https://tinyurl.com/yyhl6e2r>
- 3 Statement about graded exercise therapy in the context of COVID-19
<https://www.nice.org.uk/guidance/gid-ng10091/documents/statement>