

The ME Association
7 Apollo Office Court
Radcliffe Road
Gawcott
Buckingham
MK18 4DF

25 July 2017

Dear Sir Andrew

The NICE guideline for CFS/ME is not fit for purpose and needs a complete revision

I assume you are aware that NICE has been undertaking a stakeholder consultation process in relation to the 2007 NICE guideline (CG53) on ME/CFS.

This follows on from a decision by an expert group that was appointed by NICE to review all the new and relevant research evidence on ME/CFS.

The ME Association (MEA) is disappointed and somewhat surprised to learn that the expert group has concluded that there is no need to review or update the guideline on ME/CFS.

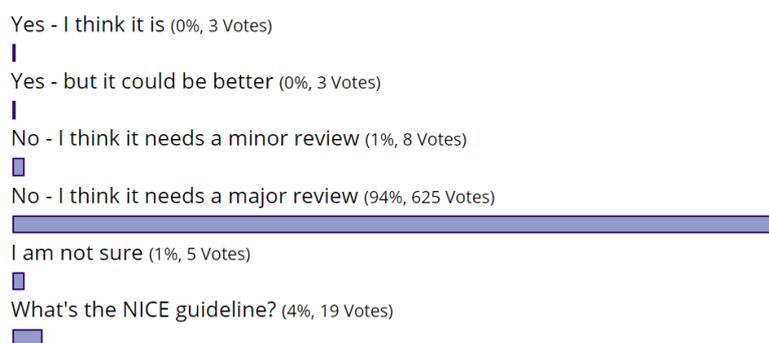
We have consistently taken the position that key parts of the 2007 NICE guideline are unfit for purpose. For example, the use of cognitive behaviour therapy (CBT) and graded exercise therapy (GET) for everyone with mild or moderate ME/CFS is not acceptable to the patient community and the undue emphasis placed on these two approaches in the guideline implies to many doctors that there is very little else that can be done to help.

We believed that a significant number of people with ME/CFS would support the MEA in calling for a proper review of the guideline, so we decided to create an online petition to allow people to demonstrate their support and to leave comments relating to their experience of clinical care under the guideline, or their own ideas about how the guideline should be revised.

The petition opened on the same day as the stakeholder consultation process began, Monday 10 July, and it closed on Monday 24 July at 9am. In the same period as that allowed for stakeholders to submit their comments to NICE, the petition was signed by 15,180 people. I attach the petition to this email – although you may also [view it online](#).

At the same time as the petition, we asked people who visit our website to complete a straw poll which asked, ‘Do you think the NICE guideline for CFS/ME is working for you?’. We began it on Tuesday 11 July and the public response can be seen on the [homepage](#) of our website but I have also taken a snapshot:

Do you think the NICE guideline for CFS/ME is working for you?



Total Voters: **663**

My understanding is that with over 15,000 signatures – the total after only two weeks – the MEA petition represents the biggest expression of no confidence in a NICE guideline ever recorded.

The ME/CFS patient community have made their views very clear. NICE must acknowledge that they have produced a guideline that is not meeting the needs of the people it is designed to help.

We also have a major cause for concern about the way in which NICE gathers and reviews what it regards as evidence in relation to acceptability, efficacy and safety of interventions used in ME/CFS.

This relates to the way in which evidence from clinicians, and especially from patients, is not being actively sought by NICE and appears to be almost completely ignored when it is submitted by patient representative organisations such as our own.

In 2002, the Independent Working Group on ME/CFS in their report to the Chief Medical Officer gave equal weight to research, clinical *and* patient evidence – and we believe this practice should be applied to the creation and review of the NICE guideline.

When evidence from clinical trials is either weak or inconsistent and there are significant differences between patient reports and clinical trial evidence – it is even more important to listen to what patients who use specialist clinics, for example, are telling you about the effectiveness and safety of the NICE endorsed recommendations.

There are many clinicians involved with the care of people with ME/CFS who are not asked to be involved in the guideline review process. However, they do have important evidence to contribute.

My colleague Dr William Weir – a well-respected specialist in infectious diseases with a longstanding interest in ME/CFS – has made the following comments:

“I think that the single most damaging misconception perpetrated on ME patients is the idea that deconditioning is the problem and that exercise is the antidote.

“I have seen many people now, well-motivated, who have made themselves much worse with exercise, often on the advice of their GPs who have been gullible enough to swallow the deconditioning hypothesis.

“I think this needs to be properly emphasised with NICE, otherwise their advice concerning graded exercise will always be assumed to be "exercise to fitness" which is always destructive.

“Sadly, the people who get worse with exercise, because they exceed their anaerobic threshold on multiple occasions with further reduction of the latter, are then assumed to be imagining their disability and treated accordingly. It would be farcical if it wasn't so serious.”

Dr Weir has asked if his comments might be added to the evidence that has already been submitted by the ME Association for the consultation.

Finally, could I draw your attention to the submission from the Countess of Mar and members of the Forward ME Group of charities:

[http://www.forward-me.org.uk/Reports/10%20year%20surveillance%20\(2017\).pdf](http://www.forward-me.org.uk/Reports/10%20year%20surveillance%20(2017).pdf)

This response focusses on the important issues of ethics and informed consent.

The NICE guideline was published in 2007 and it has not been changed in 10 years despite advances in our knowledge-base and its testing on many thousands of people with ME/CFS.

In our opinion, it is fundamentally failing to serve the need of patients and we call on you to help us work with NICE to achieve something demonstrably better.

I would welcome the opportunity to come and discuss the situation outlined by the petition and in our submission to NICE with you at your earliest opportunity.

In the meantime, I look forward to hearing your response to the petition so that I might pass your words on to our supporters.

Yours sincerely,

Dr Charles Shepherd

Hon Medical Adviser, ME Association.

Attachments in accompanying email to your PA:

1. The ME Association petition: The NICE guideline for CFS/ME is not fit for purpose and needs a complete revision - in two parts:
 - a. All those who signed the petition
 - b. All the comments that were made

2. The ME Association stakeholder submission to the NICE guideline consultation process

Copies of this letter and attachments are being sent to:

Countess of Mar - House of Lords and Chair of the Forward-ME Group
Professor Mark Baker – Centre for Guidelines Director, NICE
Dame Sally Davies - Chief Medical Officer for England at the Department of Health
Dr Martin McShane - Director of Long Term Conditions at NHS England