

August 19th 2021

Dear NICE,

As a stakeholder of the updated guidelines on the diagnosis and management of myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS), we wish to express our grave concern at the decision to pause the publication of the updated guidelines for a second time.

The reason given by NICE for the second delay implies that NICE may have been intimidated by those who do not wish to have Graded Exercise removed from the updated guidelines. NICE should be the leader of good, truthful science, which it should adhere to despite those opposing such views. If NICE caves into such pressure then it ceases to exist as the organisation it was set up to be, the lead for good scientific standards.

We urge you to publish the long-awaited draft guidelines, which after years of hard, diligent research reached the decision to omit Graded Exercise and no longer promote Cognitive Behavioural Therapy as a cure.

Yours sincerely,

Catherine Ashenfelter and the trustees of The Grace Charity for M.E.

(registered charity and NICE stakeholder)