



# Global ME community is unified in firm support for the NICE 2021 ME/CFS guideline

In rapid response to “Anomalies in the review process and interpretation of the evidence in the NICE guideline for chronic fatigue syndrome and myalgic encephalomyelitis”

<https://jnnp.bmj.com/content/early/2023/07/09/jnnp-2022-330463>

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The World ME Alliance, its 24 member organisations across 17 countries, and associated authors of this response firmly endorse NICE’s statement that they “reject entirely the conclusions drawn by the authors of this analysis, and in particular their conclusion that NICE has not followed international standards for guideline development which has led to guidance that could harm rather than help patients.”<sup>1</sup>

The authors identify eight arguments, all of which have been made and rebutted multiple times, including during an extraordinary roundtable that consequently delayed the publication of the ME/CFS guideline.<sup>2</sup> It is essential to acknowledge that these arguments have been repeatedly found to be lacking.

In line with the 2003 Canadian Consensus Criteria<sup>3</sup>, the 2011 International Consensus Criteria<sup>4</sup>, the 2015 Four Symptom Empiric Criteria<sup>5</sup>, and the 2015 National Academy of Medicine (NAM) (previously Institute of Medicine) criteria<sup>6</sup>, we support the inclusion of the post-exertional malaise (PEM) as a core symptom of ME. We also support the decision to undertake sensitivity analyses to assess whether the presence of PEM in trials affected outcomes. The authors' argument against mandatory PEM fails to note the Centers for Disease Control's current recommendation of the 2015 NAM criteria which includes PEM.

The low quality evidence ratings for research which predominantly investigated individuals with chronic fatigue, not ME, is a demonstration of the rigour with which NICE undertook this review. Advancements in best practice to diagnose ME are to be celebrated.

NICE did not “minimise” the importance of fatigue as an outcome. In fact, the committee agreed that “fatigue/fatiguability” was one of the “outcomes that matter most”.<sup>7</sup>

The application of GRADE to synthesise evidence was undertaken by an independent NICE technical team, as is standard practice.



The authors cherry pick statements from trials in relation to the definition of GET. Other statements that could be pulled out include “encourage maintenance of exercise despite an increase in symptoms” and “add 20% duration.”<sup>8</sup>

It is crucial for readers to be aware that previous studies conducted by some of these researchers were rated as low or very low quality by NICE. This information adds important context to their perspectives.

It is disappointing that these researchers did not draw more broadly on the wealth of knowledge of people with ME prior to publication.

We are concerned that this new paper will effectively encourage clinicians to offer GET to patients, perpetuating harm and increasing disability.

Given the overwhelming support of so many international patient organisations for the 2021 NICE ME/CFS guideline, it is imperative to progress beyond these outdated and repetitive arguments. Current research indicates that approximately 50% of individuals with long COVID meet the criteria for ME/CFS,<sup>9</sup> further emphasising the need to prioritise meticulous research efforts aimed at discovering treatments that truly enhance the functioning and quality of life of people with ME.

We look forward to reading NICE’s detailed response when it becomes available, but wish to make clear the unity of the international ME community in its support of the 2021 NICE guideline “Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management”.<sup>10</sup>

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## Competing Interests

The authors of this response are predominantly representatives of national patient organisations, working with their respective governments and other bodies to improve the lives of people with ME. Researchers represented here work with universities across the world to investigate ME/CFS.

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