

MEDIA STATEMENT

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

NICE has today (17 August 2021) taken the decision to pause publication of its updated guideline on the diagnosis and management of myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS).

The guideline recognises that ME/CFS is a complex, multi-system, chronic medical condition where there is no 'one size fits all' approach to managing symptoms. The causes of ME/CFS are still poorly understood and because of this there are strong views around the management of this debilitating condition.

Because of issues raised during the pre-publication period with the final guideline, we need to take time to consider next steps. We will hold conversations with professional and patient stakeholder groups to do this. We need to do this so that the guideline is supported.

NICE has used its usual rigorous methodology and process in developing this guideline but despite the best efforts of the committee, that followed these to the letter to bring together the available evidence and the real, lived experience and testimony of people with ME/CFS, we have not been able to produce a guideline that is supported by all.

We want to thank everyone who has contributed to this guideline and particularly the committee and the patient groups who have worked so diligently. However, 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.

In order to have the desired impact, the recommendations must be supported by those who will implement them and NICE will now explore if this support can be achieved.