



October 2021

The new NICE Guideline on ME/CFS was published on 29th October 2021

This is BACME's response to the publication:

BACME welcomes the new NICE Guidance on ME/CFS in the hope that this will support continued progress in improving the quality of life of all people who have the complex illness ME/CFS.

Clinicians working in NHS specialist ME/CFS services strive to provide high quality care and support to people with ME/CFS while recognising that there is still a long way to go with our understanding of the condition and we do not yet have a robust evidence base on which to guide treatments and therapy approaches.

The new NICE guideline provides information regarding diagnosis including the importance of recognising the key symptom of Post-Exertional Malaise. The guideline has also clarified the use of the term Graded Exercise Therapy (GET) and, in a change from the previous guideline, it has now restricted use of the term GET to describe therapy programmes based on treating deconditioning. The symptoms of ME/CFS are not caused by deconditioning. This guideline marks the move away from using GET programmes for treating ME/CFS. This is a move the majority of BACME members working in NHS specialist services have already made.

BACME welcomes the fact the new NICE guideline specifies that clinicians from all disciplines delivering care to people with ME/CFS should have specialist knowledge of the condition.

BACME continues to support research which aims to provide further understanding of the underlying pathological processes that generate the symptoms experienced by people with ME/CFS in the hope this will also lead to more refined therapeutic approaches.

BACME recognises the importance of providing confident support to people with ME/CFS now and would like to see increased investment in specialist service provision to ensure equitable access for all people with ME/CFS.

BACME will use the new NICE guideline as a foundation on which to build further clinical guidance on the delivery of care to people with ME/CFS and work to ensure that the patient story is heard and embedded in the future of ME/CFS care.