

Critical analysis of the 2021 NICE Guidelines: moving away from GET and CBT in ME/CFS

Key message: In 2021, NICE fundamentally revised the earlier positive view of Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) for ME/CFS. GET should not be offered when it is based on fixed increases in activity. CBT is not understood as a treatment for the disease itself, but at most as optional supportive psychological help for coping with the impact of illness.

Context

Guideline NG206 from the National Institute for Health and Care Excellence (NICE) replaced the previous UK guideline on ME/CFS in 2021. NICE analysed CBT and GET in detail according to predefined scientific criteria. The main reasons for downgrading the evidence were risks of bias, indirect study populations, inconsistent findings and imprecise estimates.

Why the evidence is weak

According to NICE, the evidence for CBT and GET was mostly **low to very low certainty**. This matters: many studies were not blinded, relied mainly on subjective outcomes such as self-reported fatigue or function, included patients using older diagnostic criteria where Post-Exertional Malaise (PEM) was not always required, and differed substantially in interventions, comparison groups and outcomes. For decision-makers, this means that the studies do not provide robust evidence that GET or CBT reliably improves ME/CFS, restores work capacity or changes the course of the disease.

Intervention	Evidence reviewed by NICE	Quality / limitations	NICE conclusion
GET Graded Exercise Therapy	12 randomised studies in adults. Programmes differed, but often involved fixed increases in the duration or intensity of physical activity.	Low to very low certainty. Common limitations included unblinded studies, subjective outcomes, heterogeneous interventions, unclear or older diagnostic criteria, and the fact that Post-Exertional Malaise (PEM) was often not required for inclusion. Harms were recorded only in limited and inconsistent ways.	Do not offer programmes based on fixed stepwise increases in activity or exercise, including GET.
CBT Cognitive Behavioural Therapy	15 RCTs in adults and 4 RCTs in children and young people. Formats and comparison groups varied.	Low to very low certainty. Many outcomes showed no clinically important difference; reported benefits were inconsistent. The evidence was limited by lack of blinding, subjective outcomes, heterogeneity and indirect applicability.	Not a curative or disease-modifying treatment. Offer only as optional supportive therapy, if the person wants it after being informed and if ME/CFS-specific expertise is available.

GET: NICE rejects fixed-increase programmes

NICE defines GET, for the purpose of the guideline, as a therapy in which a baseline level of physical activity is first established and then duration or intensity is increased in fixed steps. This approach was historically based on deconditioning and avoidance models. NICE found no sufficiently reliable evidence to support it and also considered patient reports of deterioration, push-crash patterns and pressure to increase activity. In the context of PEM, NICE regards fixed-increase programmes as problematic because they contradict the core principle of staying within individual energy limits.

CBT: supportive only, not disease-modifying

NICE found more studies on CBT than on many other non-pharmacological approaches, but the evidence was still weak and inconsistent. NICE explicitly states that CBT neither cures ME/CFS nor treats the disease itself. CBT must not be based on the assumption that ME/CFS is caused by false illness beliefs or dysfunctional behaviour. It may be considered only as an optional form of support, for example to help with distress, sleep problems, the consequences of chronic illness or associated psychological strain, and only with informed consent and ME/CFS-specific expertise.

Practical implication

The practical message for care and policy is clear: GET should not be used as a standard offer, rehabilitation target or condition for benefit eligibility. CBT may be useful if a person wants it, but it must not be presented as a curative therapy, an activation programme or indirect evidence of a psychological cause. NICE shifts the focus away from standardised activation programmes and towards informed consent, symptom limits, protection from overexertion and transparent communication about the uncertainty of the evidence.

Source

NICE. *Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management*. NICE Guideline NG206, 2021. NICE. *Evidence review G: non-pharmacological management of ME/CFS*, 2021. NICE. *Evidence review H appendices*, 2021. Additionally considered: Kingdon et al. 2022; Vink & Vink-Niese 2020, 2022.