

Position Statement

2021 NICE Guideline Update on Treatment and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

On the 10th of November 2020, the National Institute for Health and Care Excellence (NICE) published its draft updated guideline on the diagnosis and management of myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS). NICE has updated its 2007 recommendations on the use of psycho-behavioural treatments for ME/CFS, concluding that Graded Exercise Therapy (GET) should no longer be offered to patients and that Cognitive Behavioural Therapy (CBT) is not a treatment or cure for ME/CFS.

Doctors with M.E. (DwME) welcomes and supports this change in treatment recommendations, and we await publication of the final guideline in August 2021. NICE undertook an extensive evidence review and consultation process that involved a wide range of stakeholders, including many clinical experts and patient groups. DwME fully supports NICE's decision to no longer recommend GET as treatment for ME/CFS. Unstructured exercise or exercise programmes developed for the rehabilitation of patients with other conditions are also not recommended. There is now considerable evidence showing that GET is an ineffective treatment for ME/CFS. Furthermore, there is widespread evidence that GET is harmful – ME/CFS patients suffer a worsening of symptoms and/or chronic deterioration in disease severity after undertaking GET.

We concur that CBT is not a treatment or cure. Psycho-behavioural therapies are premised on a refuted model in which ME/CFS is the result of patients holding on to 'false illness beliefs' and is perpetuated by patient's 'fear avoidance of exercise'. This 'biopsychosocial model' of ME/CFS has arguably led to decades of acrimony between the medical professionals who advocate this approach and patients, which has caused considerable distress to many people living with ME/CFS worldwide. Current scientific understanding demonstrates that ME/CFS is a complex multi-system biological disease that profoundly impacts the lives of sufferers, causing disabling symptoms such as extreme fatigue, pain, cognitive impairment, orthostatic intolerance, sleep disturbance and post-

exertional malaise (PEM) /post-exertional symptom exacerbation (PESE). Many patients with the disease stop seeing doctors after encountering disbelief and lack of understanding.

DwME considers the 2021 NICE guideline to be a watershed moment in the history of ME/CFS medical care in the UK. The new guideline supports a change in ME/CFS treatment towards evidence based foundations, away from psychological therapies and adopting a more physiological and patient-centred approach. There is an opportunity for doctors and patients to come together to develop more concordant and productive relationships, whereby GPs and other specialists are supported in offering symptom treatment and compassionate care to people living with ME/CFS.

The removal of GET as a recommended treatment and the downgrading of CBT to being no more than a supportive therapy paves the way for a new era in ME/CFS scientific inquiry and improved clinical care. The Covid-19 pandemic has demonstrated in stark terms that viral illnesses can result in post-viral syndromes that linger for long periods and debilitate patients. There has been huge demand for appropriate 'Long COVID clinics' laying bare the gaps in the existing model of care and the shortcomings of psycho-behavioural therapies. DwME will be monitoring research developments in this field. We hope that improved understanding of Postacute COVID-19 Syndrome or 'Long COVID', together with the revised NICE guideline for ME/CFS, will act as an impetus for funding bodies to support more high quality biomedical ME/CFS research studies and improved clinical care.