

NICE Publishes new Guideline on ME/CFS*, driving major improvements in care

Press Statement from Forward-ME, embargoed until publication of NICE guidelines.

Doctors, and people with ME* welcome the new NICE guideline on ME/CFS, which brings major improvements to the diagnosis, management and support for people with ME.

The new guideline on ME/CFS sets out a significant change in approach:

- Recommending 'Energy Management' techniques to avoid 'Post-Exertional Malaise' and exacerbation of symptoms. This approach recommends people with ME plan their physical and cognitive activities to stay within their energy limits, incorporating rest where necessary. This is also known as 'Pacing'.
- Maintains the use of Cognitive Behavioural Therapy (CBT) only to help people cope with the distress which can accompany a long term condition, but recognises that CBT cannot cure ME.
- Child safeguarding is significantly improved. Some parents of children with ME have been subjected to inappropriate child protection orders, and threatened with the removal of their children, in the belief that the parents had caused a 'fabricated or induced illness'.

The recommendations on 'Energy Management' will also help people with LongCovid who experience Post-Exertional Malaise (PEM), many of whom have reported that 'Graded Exercise Therapy' worsened their condition, and their symptoms were dismissed as anxiety.

This recommendation is a clear break from the past. Previously, people with ME were offered 'Graded Exercise Therapy' (GET), based on a hypothesis that they were deconditioned. NICE found the evidence for this to be poor quality, and many people with ME reported that GET caused serious harm.

The new guideline on ME/CFS was due to be published in August, but NICE 'paused' the release following intervention from some clinicians. After a round-table with representatives from the 'Royal Colleges' and ME charities, NICE is now confident that the guideline can be fully implemented.

COMMENT:

"The new NICE guideline is welcomed because it acknowledges the truth of people's experiences, and creates a foundation for hope that in the future, children and adults with ME will receive an improved standard of care and support." (*Sonya Chowdhury, CEO, Action for ME*)

"We hope and believe the Guideline will provide much needed stimulus for substantial, publicly funded biomedical research into the causes, consequences and treatment of this disease." (*Jonathan Davies, ME Research UK*)

"This is a very special day for people with ME - publication of a new evidence-based NICE guideline which confirms that this is a serious and very debilitating medical disease. I welcome the emphasis on early and accurate diagnosis and the need to provide early guidance on symptom management when people are not recovering from a viral infection and a diagnosis of ME is suspected." (*Dr Charles Shepherd, Medical Advisor, ME-Association*)

"The Guideline should drive better acceptance of ME as serious medical condition and encourage doctors to personalise care based on individual needs. It is a real opportunity for doctors to transform the care patients receive." (*Dr David Strain, Medical Advisor: Action for ME*)

***NOTES:**

- ME/CFS, short for 'Myalgic Encephalomyelitis' / 'Chronic Fatigue Syndrome', is a chronic disease characterised by long-term, debilitating loss of energy, often accompanied by pain. The defining symptom of ME is 'Post-Exertional Malaise', the disproportionate worsening of symptoms

after exertion that can last days, months or years.

- People with ME often experience other symptoms such as cognitive dysfunction (known as 'brain fog'), heart rhythm disorders and neurological effects. People with severe ME can be bed-bound for years, with hyper-sensitivity to light and sound. Some require tube-feeding.
- There is currently no cure for ME, but effective management can reduce symptoms.
- ME charities avoid the phrase 'Chronic Fatigue Syndrome' because 'fatigue' under-represents the severity of the disease and ignores many of the symptoms.
- Forward-ME represents national ME charities, co-ordinating activity to support people with ME.