

ME/CFS: Recent changes in the scientific understanding and standards of clinical practice

The scientific understanding of ME/CFS has changed dramatically in recent years, as have standards of clinical practice. The 2021 NICE guidance on ME/CFS, which was produced following an exhaustive review of the scientific evidence and consultation with researchers, clinicians, and patient groups, is very different from the 2007 guidance which preceded it. Some examples of the recent changes:

- In the past ME/CFS has been viewed by some medical professionals as a minor illness that generally resolves on its own. NICE now recognizes that ME/CFS is a very serious chronic illness with no cure.¹ 75% of sufferers are unable to work or attend school, and 25% are housebound.²
- In the past some have viewed ME/CFS as rare. In fact, according to NICE its pre-pandemic prevalence was around 0.4%³, and since 2019 the number of people developing ME/CFS following a covid-19 infection has continued to rise.^{4,5,6,7}
- While the 2007 NICE guidance on ME/CFS put forward the view that the condition might be psychological or partly psychological, the 2021 guidance confirms that ME/CFS is a serious chronic illness which affects multiple body systems, with abnormalities in the nervous, immune, and cardiovascular systems and in cellular metabolism.^{3,8}
- While the 2007 NICE guidance on ME/CFS recommended cognitive behavioural therapy (CBT) as a curative treatment, the 2021 guidance confirms that CBT does not cure ME/CFS or treat its symptoms.⁹
- While the 2007 NICE guidance on ME/CFS recommended graded exercise therapy (GET), we now know that people with ME/CFS have an abnormal physiological response to exercise such that exercise can be uniquely harmful for them. 'Pushing through' the discomfort to stick to an exercise program causes post-exertional malaise and is associated with a permanent worsening of disease severity.^{10,11,12,13,14}
- Even the name has been updated. In the past the term 'chronic fatigue syndrome' was widely used, but patient groups have argued that this term minimizes and stigmatizes what is in fact a very serious medical condition, while researchers have rejected it as overly vague and technically inaccurate.

Unfortunately the new scientific understanding and clinical standards have not yet made their way into the medical education system. Studies show that:

- Most doctors have had no training on ME/CFS, and don't feel confident dealing with patients who have the condition. Many have false beliefs about ME/CFS.^{16,17,18,19}
- ME/CFS is not generally taught in medical schools at the undergraduate level, and medical students have little understanding of the condition.^{20,21,22}

- In the world of medicine there exists a culture of stigma towards patients with ME/CFS.^{23,24,25,26,27,28}

References

‘NICE’ is used as shorthand for: NICE guideline [NG206] Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome. <https://www.nice.org.uk/guidance/ng206>

1. NICE 1.11.1

2. NICE Box 1

3. NICE Context

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9. NICE 1.12.28 and Box 5

10. NICE Recommendations and NICE Box 2

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