

Action for M.E. summary of the National Institute for Health Excellence (NICE) guideline for M.E./CFS, draft for consultation, November 2020

**Section 1.2 Suspecting M.E./CFS**

**Key messages for this section**

- There is currently no diagnostic test for M.E./CFS, with the illness being recognised on clinical grounds alone.
- M.E./CFS should be suspected if the person's ability to engage in various activities is significantly reduced from pre-illness levels, and if the following symptoms are new, had a specific onset and have persisted for 6+ weeks in adults or 4+ weeks in children:
  - debilitating *fatigability*\* that is not caused by excessive cognitive, physical, emotional or social exertion and is not significantly relieved by rest **AND**
  - post-exertional malaise after activity that is delayed in onset by hours or days, is disproportionate to the activity, or has a prolonged recovery time **AND**
  - unrefreshing sleep **AND**
  - cognitive difficulties/brain fog

*\*Fatigability is defined as having the following features:*

- *sick or 'flu-like' fatigue, especially in the early days of the illness*
  - *'wired but tired' fatigue, or restless fatigue (it may also include hypervigilance during sleep)*
  - *low energy or a lack of physical energy to start or finish activities of daily living and the sensation of being 'physically drained'*
  - *cognitive fatigue that worsens existing cognitive difficulties*
  - *rapid muscle fatigue in which strength or stamina are lost quickly after starting an activity, causing sudden weakness, clumsiness, lack of coordination, and being unable to repeat physical effort consistently.*
- People with suspected M.E./CFS should receive assessments that include:
    - a comprehensive clinical history
    - a physical examination
    - a psychological wellbeing assessment
    - baseline investigations to exclude other diagnoses.
  - If M.E./CFS is suspected based on the above criteria, clinicians should not delay in making a provisional diagnosis (while continuing with tests needed to exclude other conditions if necessary) and offering advice on symptom management.
  - GPs should consider seeking advice from an appropriate specialist if they are uncertain about interpreting signs and symptoms, and whether a referral is needed; suspected M.E./CFS in a child or young person should be referred to a specialist paediatrician.

**For more information about the NICE guideline for M.E. or to share your view, please visit [www.actionforme.org.uk/NICE](http://www.actionforme.org.uk/NICE)**