

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

## Section 1.4 Diagnosis

### Key messages for this section

- Children and adults may be diagnosed with M.E./CFS once all symptoms listed in recommendation 1.2.3 have persisted for three months (this is revised from four months for adults in the 2007 guideline).
- Symptoms listed in recommendation 1.2.3 include:
  - 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.*

### Health and social care professionals should:

- After a diagnosis, refer adults directly to a specialist team experienced in managing M.E./CFS to develop a management plan.
- After a diagnosis in a child by a paediatrician, refer them directly to a paediatric specialist team experienced in M.E./CFS to develop a management plan.

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)