

ME/CFS

a recognised condition, and the guidance has changed

Myalgic encephalomyelitis, also called chronic fatigue syndrome, is a long-term condition causing profound fatigue, post-exertional worsening, unrefreshing sleep and cognitive difficulty. NICE guidance was substantially rewritten in 2021, and much of the advice people were given for decades is no longer recommended.

Seek assessment before assuming ME/CFS if you have

- **fever, night sweats or unexplained weight loss**
- **swollen lymph nodes** that persist, or a new lump
- **severe headache, weakness or visual changes**
- **fatigue in a child or young person**, which needs specialist assessment
- **thoughts of harming yourself**

Fatigue has many treatable causes. Anaemia, thyroid disease, coeliac disease, diabetes, sleep apnoea, depression, vitamin deficiency and medication side effects all produce it, and all are found by straightforward testing. If you are struggling with your mood, Samaritans are free on 116 123 at any hour.

What is required for the diagnosis

All four must be present, for at least three months, and be significantly disabling:

- **Debilitating fatigue** that is worsened by activity, not caused by excessive exertion, and not significantly relieved by rest
- **Post-exertional malaise** — symptoms worsening after activity, often **delayed by hours or days** and disproportionate to the effort
- **Unrefreshing sleep**, or disturbed sleep patterns
- **Cognitive difficulties** — brain fog, poor concentration, slowed processing, word-finding problems

What changed in 2021

NICE withdrew its previous recommendations for **graded exercise therapy** as a treatment for ME/CFS, and reframed CBT as support for coping with a chronic illness rather than a cure. It also stated clearly that ME/CFS is **not** a psychological condition and should not be treated as deconditioning or false illness beliefs. If you are offered a programme that requires you to increase activity on a fixed schedule regardless of symptoms, that is not current guidance.

Energy management

The central approach is staying within your energy limits rather than trying to expand them by pushing. This is not giving up; it is the intervention with the best chance of stabilising and slowly improving things.

- **Establish your baseline** — what you can do on a bad day without a crash. Live at or below it.
- **Plan, pace and prioritise.** Split tasks, rest between, sit rather than stand where possible.
- **Count all forms of exertion** — physical, cognitive, emotional, sensory and social.
- **Rest proactively**, not only when exhausted. Rest means genuine rest, not scrolling.
- **Increase only after sustained stability**, and by small amounts, prepared to step back.
- Manage sleep, orthostatic symptoms, pain and nausea specifically — each has treatments.

What should be tested

There is no diagnostic test for ME/CFS, so the diagnosis rests on the criteria plus exclusion of alternatives. Baseline testing should include a full blood count, inflammatory markers, ferritin, B12, folate, thyroid function, kidney and liver function, calcium, glucose or HbA1c, coeliac screening, vitamin D and a urine test. Further tests are added where the history suggests them.

Practical support

- ME/CFS can meet the definition of a disability under the Equality Act 2010 — reasonable adjustments at work or in education can be requested.
- Detailed evidence letters help with PIP, Access to Work, university disability services and blue badge applications.
- Severe ME/CFS can leave people housebound or bedbound, needing home visits and adapted care. This is recognised in the guidance and should not be met with scepticism.
- Action for ME and the ME Association both provide information and advocacy.

Why come to us. People with ME/CFS are frequently disbelieved, rushed, and told to exercise more. We offer unhurried appointments with time to take a proper history, the full exclusion panel taken in-house with results explained face to face, and management aligned with current NICE guidance rather than the version it replaced. We provide detailed fit notes and supporting letters for work, education and benefits, and can refer for symptom-specific input. Seven days a week, on one clinical record.

Believed, tested properly, and supported

Unhurried appointments and full exclusion bloods in-house. Seven days a week.

Book an appointment

or call 020 7916 0029

Where to get help

Tower Bridge Hospital London

97–99 Whitechapel Road, London E1 1DT

020 7916 0029

WhatsApp **07903 284 189**

info@mhwclinic.co.uk

Open 7 days, 9am–7pm

In an emergency

Call 999, or go to the Royal London Hospital Emergency Department, Whitechapel Road, London E1 1FR.

When we are closed and it is not an emergency

Call NHS 111 or visit 111.nhs.uk.

Related: **[Private GP Services](#)** · **[Blood Tests](#)** · **[Sick Notes / Fit Notes](#)** · **[DWP / PIP Support Letter](#)** · **[All patient leaflets](#)**

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This leaflet is based on current NHS and NICE NG206 guidance on myalgic encephalomyelitis (or encephalopathy) / chronic fatigue syndrome. It is general information and does not replace advice from a clinician who has assessed you. If your symptoms change or you are worried, contact us on 020 7916 0029, call NHS 111, or call 999 in an emergency.

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