



Quick guide to myalgic encephalomyelitis (ME)

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What is myalgic encephalomyelitis?

Myalgic encephalomyelitis (ME; sometimes called chronic fatigue syndrome or ME/CFS) often occurs after a stress to the body, such as infection or vaccination. ME is poorly characterised clinically but research shows multiple body systems are affected, resulting in pathologies such as: mitochondrial, immunological, neurological, and/or endocrine dysfunction; coagulopathy; (neuro-)inflammation; autoimmunity; cardiovascular abnormalities; connective tissue problems; reactivated pathogens; and hypoperfusion, among other things.

What are the symptoms of myalgic encephalomyelitis?

Whilst ME is characterised by fatigue, unrefreshing sleep, cognitive dysfunction, and post-exertional symptom exacerbation (PESE), it is a whole-body, all-consuming disease. Therefore, patients can experience a range of other symptoms which may be fluctuant (i.e. “flares” or “relapses”), including:

General:

Flu-like symptoms
Food and/or chemical sensitivities
Insomnia
Loss of fingerprints and/or extra lines across the fingerprints
Muscle aches
Polydipsia

Lungs & cardiovascular:

Dyspnoea
Palpitations

Genitourinary:

Polyuria

Ears, nose, throat, & eyes:

Eye ache
Swollen/tender glands

Gut:

Appetite changes
Diarrhoea and/or constipation
Gastrointestinal problems
Nausea

Neurological:

Headaches
Neuromuscular problems (e.g. myoclonic jerks)
Orthostatic intolerance
Sensory hypersensitivity/overload
Thermodyregulation
Paraesthesia
Dizziness
Pain

How is myalgic encephalomyelitis diagnosed?

After ruling out differential diagnoses, UK NICE guidelines require the following to be present for ≥ 3 months:

1. Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional, or social exertion, and is not relieved by rest
2. Post-exertional malaise (PEM; also called PESE or post-exertional neuroimmune exhaustion) after activity in which the worsening of symptoms:
 - a) Is often delayed in onset by hours or days
 - b) Is disproportionate to the activity
 - c) Has prolonged recovery time that may last hours, days, weeks, or longer
3. Unrefreshing sleep and/or sleep disturbance, which may include:
 - a) Feeling exhausted, feeling flu-like and stiff on waking
 - b) Broken or shallow sleep, altered sleep pattern or hypersomnia
4. Cognitive difficulties (sometimes described as “brain fog”), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking

A note on PESE:

PESE has been objectively demonstrated in research using two-day cardiopulmonary exercise testing (CPET), showing a physiological reduced capacity for activity (e.g. significantly lower peak oxygen consumption [VO_2 peak]). This response to repeat exercise is **not** seen in other conditions such as multiple sclerosis, deconditioning, or heart failure.

What tests are there for myalgic encephalomyelitis?

There are currently no clinically available tests that can detect ME. UK NICE guidelines recommend checking at least the following to exclude other diagnoses:

- Urinalysis for protein, blood, and glucose
- Full blood count
- Urea and electrolytes
- Liver function tests
- Thyroid function tests
- Erythrocyte sedimentation rate or plasma viscosity
- C-reactive protein
- Calcium and phosphate
- Glycated haemoglobin
- Ferritin
- Coeliac screen
- Creatine kinase

Alongside the above, NICE state: Use clinical judgement to decide on additional investigations to exclude other diagnoses (for example, vitamin D, vitamin B₁₂ and folate levels; serological tests if there is a history of infection; and 9am cortisol for adrenal insufficiency).

Common comorbidities for ME are mast cell activation syndrome, dysautonomia (including postural orthostatic tachycardia syndrome), and hypermobile Ehlers-Danlos syndrome. Screening for these (and related conditions) may therefore be appropriate.

What treatments are there for myalgic encephalomyelitis?

There are currently no approved treatments for ME; therefore, UK NICE guidelines are based on symptom management only. Referrals to specialists may be necessary, as well as a ME specialist team.

Energy management:

The main focus is on energy management (commonly called pacing). Energy management includes considering exertion from physical, cognitive, emotional, and social activities, as well as sensory stimulation. Small meals, noise cancelling headphones, and/or tinted glasses may be helpful for some patients to aid wider pacing strategies.

Symptom management:

NICE recommend following current pathways, where appropriate, to help certain symptoms (e.g. pain, unwanted weight loss).

Comorbidities:

Comorbidities should be managed appropriately, being aware that patients with ME can be highly sensitive to medications, so titrating slowly from a subtherapeutic dose may be required.

Exercise should not be recommended:

Exercise or increasing physical activity (including graded exercise therapy) is contraindicated in ME and can result in permanent worsening of the patient's condition.

Other treatments:

Research is ongoing regarding more direct ME treatments. Some research papers are on the **Resources** page if you would like to read about these, though they are not endorsed by NICE.

Resources

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Disclaimer

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