Diagnosis & management of myalgic encephalomyelitis

Myalgic encephalomyelitis (ME) is a chronic, debilitating disease with progressive or fluctuating course. It affects approximately 1.3 million Americans.

Other names:

Patients may have been given a diagnosis of ME/CFS or chronic fatigue syndrome.

Category:

Neurological

Body systems:

Notable signs and symptoms are found in the **central** and **autonomic** nervous systems, the **cardiovascular** system, the **gastrointestinal** system, and the **immune** system. Due to the involvement of the central and autonomic nervous systems, other body systems may also be affected.

Onset and Risk Factors

80% of patients report first developing symptoms after an acute infection. Common viral triggers include **herpesviruses** (Epstein-Barr, cytomegalovirus, HHV-6, HHV-7) and **enteroviral infections** such as Coxsackie B.

Less common triggers (<20%) include **non-infectious immune challenges**, such as anesthetics; physical trauma like surgery, concussion or car accident; and chemical exposure.

Studies have found that susceptibility to ME may be **genetic**. Individuals with first-degree relatives with ME were found to be **twice as likely** to develop the disease

People of all ages, races, and genders can contract ME.

Diagnosis

ME patients must show the following symptoms:

- ✓ A **reduction/impairment in ability to engage in pre-illness activity** that persists for 6 months or more
- ✓ **Fatigue** that is profound, not lifelong, not the result of ongoing exertion, and **not alleviated by rest**
- ✓ **Post-exertional malaise** (PEM) in which physical or mental activities result in a delayed exacerbation of symptoms and reduction in functioning
- ✓ **Unrefreshing sleep**
- ✓ **Cognitive impairment** and/or **orthostatic intolerance**

These core features of illness must be moderate to severe and present at least 50% of the time.

Other common symptoms

- **Pain** in the muscles and joints
- **Headaches** of a new type, pattern, or severity
- **Cognitive symptoms** such as confusion, difficulty retrieving words, poor working memory, spatial instability, and disorientation
- **Sensitivity** to light, sound or vibration, taste, odor or touch
- **Gastrointestinal** symptoms such as nausea or abdominal pain
- **Muscle fatigability**, **weakness** and **fasciculation**; poor coordination and ataxia
- **Autonomic** and **endocrine** symptoms such as poor temperature regulation, cold or heat intolerance
- **Immune** symptoms such as tender lymph nodes, recurrent sore throats, fevers, or **flu-like symptoms**, and new food or chemical sensitivities

Patients may have many or even all symptoms listed; however, severity of each symptom will vary patient to patient.

Understanding post-exertional malaise (PEM)

Post-exertional malaise (PEM) can help distinguish ME from other diseases. PEM is a **significant and prolonged worsening of all symptoms after sustained physical or mental activity.** It's important to know that overexertion can damage a patient's health, sometimes permanently – and that patients **cannot** be cured by gradually increasing their exercise over time.

Patients experiencing PEM may have additional difficulty speaking, reading, and communicating. They may have worsened pain, with limbs tingling or numb, and their locomotor ability may be so compromised that they're effectively paralyzed until the episode passes.

After an episode of PEM, it may take days, weeks, or even months for the patient to return to their previous baseline.

Course of post-exertional malaise

- PEM **may be delayed** after the triggering activity, often by 24 hours
- The amount of physical or cognitive activity that results in PEM will **vary patient to patient**
- The amount of physical or cognitive activity may vary **for the same patient at different times**
- Recovery time is **not necessarily proportional** to the intensity of the triggering activity
- Using wearables, apps, and symptom diaries to **help your patient identify triggering events** is one of the most useful interventions to help prevent future episodes of PEM. (See 'Pacing' within Management section).

Additional resources for clinicians:

National Academy of Medicine, Myalgic encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness
Myalgic Encephalomyelitis: International Consensus Criteria
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: a Primer

Disease course and prognosis

On average, patients with myalgic encephalomyelitis have a lower quality of life score (QOL) and are more disabled than patients with diabetes, colon cancer, multiple sclerosis, and chronic renal failure. **One of four ME patients is housebound or bedbound.** However, **severity may fluctuate** in the same individual **over time** and **day by day**, meaning the snapshot you see in a typical office visit can be misleading.

People with ME range from functional with accommodations to bedbound and tube-fed with extreme sensitivities to light and noise. It's important to understand the spectrum because severe patients may improve over time, and mildly-affected patients can get worse. Early diagnosis and management is key.

There is no known cure for ME, though up to 5% of adults with the condition may make a full recovery. In addition, there is a lot you can do to help patients improve their quality of life.

Comorbidities and diagnostic tools

Common comorbid conditions

- Postural tachycardia syndrome (POTS) and other orthostatic intolerance (OI)
- Hypermobility and Ehlers-Danlos Syndromes (EDS)
- Mast cell activation disorder (MCAS, MCAD)
- Small intestinal bacterial overgrowth (SIBO)
- Fibromyalgia
- Celiac disease
- Primary sleep disorders
- Allergies and chemical and food intolerances (IgE/IgG)
- Secondary depression/reactive depression

Lab findings and diagnostic tools

- Autoantibodies
  - Thyroid peroxidase (as in Hashimoto's thyroiditis)
  - Alpha and beta adrenergic
  - Muscarinic cholinergic (as in dysautonomia)
- Immune deficiencies
  - IgG subclass deficiency
  - IgA deficiency
  - B cell or CD19 deficiency
  - Low natural killer cell function (common)
- Autonomic panel and/or basic autonomic clinical testing
  - NASA lean test

Management

Pacing

Pacing is the practice of maintaining activity within the patient's safe range, or 'energy envelope'. Pacing can help prevent post-exertional malaise. The following management approaches may be useful:

- Use a **wearable device** to measure heart rate/activity
- Maintain a symptom, activity and medication **diary**
- Monitor cognitive and physical activity on a usual day and **reduce that activity** by 25%
- Break strenuous activity into **smaller tasks**, with **rest**

Since PEM symptoms may be delayed, a diary is of significant utility for patients.

Activity induces a pattern of gene expression, inflammation, and metabolic dysfunction that cannot be explained by deconditioning and may be unique to people with ME. **The NAM and CDC no longer recommend graded exercise for patients with ME.** Moreover, patients report that overexertion can permanently reduce their energy envelope.

Orthostatic intolerance

Patients with orthostatic intolerance (OI) should increase their water intake to at least 2-L a day and increase electrolytes and salt intake. Other helpful interventions include:

- Beta-blockers for POTS
- Fludrocortisone and midodrine or pyridostigmine
- IV saline

People with ME may be very sensitive to medications. Start low and raise to an effective dose over time.

Pain and Sleep

For patients where pain is a primary symptom, the following medications may be helpful:

- NSAIDS such as Celecoxib or low-dose naltrexone
- Tramadol

Most patients have disordered sleep. Sleep hygiene practices may not be enough to restore healthy sleep, and may not be practical for patients who are housebound or bedbound. Sleep medications may help close the gap.

Patients often find that if they are able to sleep well, other symptoms improve.

Other ways to support patients

- Check patients for nutritional deficiencies, including B vitamins, Vitamin D, and iron. While these are not the cause of ME, low levels can contribute to debility.
- Patients with sensory sensitivities may be helped by ear plugs and eye masks or sunglasses.
- The use of wheelchairs and handicapped parking stickers may reduce PEM.
- Patients may also need support in obtaining disability benefits and accommodations in school or at work.

ME is a complex, often lifelong illness, but caring physician support can make an enormous difference in the lives of patients. Thank you for making the commitment to learn more!

To learn more, visit meaction.net