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

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.

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.

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.

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

<table>
<thead>
<tr>
<th>Common comorbid conditions</th>
<th>Lab findings and diagnostic tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Postural tachycardia syndrome (POTS) and other orthostatic intolerance (OI)</td>
<td><strong>Autoantibodies</strong></td>
</tr>
<tr>
<td>Hypermobility and Ehlers-Danlos Syndromes (EDS)</td>
<td>o Thyroid peroxidase (as in Hashimoto’s thyroiditis)</td>
</tr>
<tr>
<td>Mast cell activation disorder (MCAS, MCAD)</td>
<td>o Alpha and beta adrenergic</td>
</tr>
<tr>
<td>Small intestinal bacterial overgrowth (SIBO)</td>
<td>o Muscarinic cholinergic (as in dysautonomia)</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td><strong>Immune deficiencies</strong></td>
</tr>
<tr>
<td>Celiac disease</td>
<td>o IgG subclass deficiency</td>
</tr>
<tr>
<td>Primary sleep disorders</td>
<td>o IgA deficiency</td>
</tr>
<tr>
<td>Allergies and chemical and food intolerances (IgE/IgG)</td>
<td>o B cell or CD19 deficiency</td>
</tr>
<tr>
<td>Secondary depression/reactive depression</td>
<td>o Low natural killer cell function (common)</td>
</tr>
<tr>
<td><strong>Autonomic panel and/or basic autonomic clinical testing</strong></td>
<td>o NASA lean test</td>
</tr>
</tbody>
</table>

### 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.

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

#### 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!**

#ME ACTION

To learn more, visit [meaction.net](http://meaction.net)