PREVALENCE

Before COVID-19, the global prevalence of ME ranged between **0.2%** and **2.6%**. It affects all age groups (including children and adolescents), ethnicities, and social classes. Although ME is most commonly diagnosed between ages **20 and 45**, the highest incidence is observed in children and adolescents (ages 10-19) and adults (ages 30-39). The majority of diagnosed cases occur in women. It is estimated that **up to 90% of affected individuals remain undiagnosed.**

TREATMENT OPTIONS

- There is no specific treatment that can cure ME or lead to significant improvement.
- **Symptomatic treatment** is highly individualized and generally has little to no proven efficacy.
- **PACING**: A strategy focused on managing and regulating activity levels to stay within energy limits and prevent **Post-Exertional Neuroimmune Exhaustion (PENE)**.

TREATMENTS THAT SHOULD NOT BE RECOMMENDED

- **Exercise-based therapies, including graded exercise therapy (GET).**
- **Cognitive-behavioral therapy (CBT).**

IMPACT ON PATIENTS' LIVES

People with Myalgic Encephalomyelitis experience significant limitations and disabilities in their daily lives. In most cases, symptoms prevent them from working, socializing, or performing household tasks. They may also struggle with caring for their families, traveling, or even completing basic self-care activities such as bathing, dressing, or cooking

In mild cases, functional capacity is reduced by at least 50%. In severe and very severe cases (**about 25% of patients**), individuals are bedridden, develop intolerance to sensory stimuli (such as light and sound), and require daily assistance for basic needs. Some may even require additional medical support, such as oxygen therapy or enteral feeding.

For more information, contact us at
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SEMG Sociedad Española de Médicos Generales y de Familia

ONG PEM

MYALGIC ENCEPHALOMYELITIS

Sometimes referred to as Chronic Fatigue Syndrome (CFS) or as ME/CFS

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WHAT IS MYALGIC ENCEPHALOMYELITIS?

Sometimes referred to as Chronic Fatigue Syndrome(CFS) or as ME/CFS.

Myalgic Encephalomyelitis (ME) is a **chronic, multisystemic disease** that severely affects patients' health and quality of life. It is an **acquired, complex, and difficult-to-manage disease** characterised by **pathological dysregulation** of the nervous, immune, and endocrine systems, along with impaired cellular energy metabolism and ion transport.

It has been recognised as a neurological disease by the World Health Organisation (WHO) since 1969.

(ICD-10 G93.32 and ICD-11 8E49).

ETIOPATHOGENESIS AND DIAGNOSIS

The **etiopathogenesis** of ME remains unknown but is likely multifactorial, involving genetic, environmental, and infectious factors, such as enteroviruses, Epstein-Barr virus (EBV), human herpesvirus (HHV-6 and HHV-7), cytomegalovirus, parvovirus B19, SARS and MERS coronaviruses, endogenous retroviruses, bacteria, fungi, or parasites.

Approximately **10%** of individuals who experience an infection may develop Myalgic Encephalomyelitis to varying degrees.

Diagnosis is clinical and differential in order to rule out other pathological entities.

The **2011 International Consensus Criteria (ICC)** should be used, as they are the most specific and up-to-date based on scientific evidence.

DISTINCTIVE AND MAIN FEATURE

POST-EXERTIONAL NEUROIMMUNE EXHAUSTION (PENE): A **pathological inability** to generate the necessary energy, primarily presenting with neuroimmune symptoms.

Key characteristics:

- Rapid and intense physical and/or cognitive fatigability following exertion, which may be minimal (e.g., daily activities or simple mental tasks) and can include even enjoyable activities such as social gatherings, attending a class, or reading a book. This can be debilitating and cause a relapse.
- Worsening of symptoms and further loss of functional capacity.
- Symptom exacerbation disproportionate to the level of activity or effort exerted.
- PENE can happen immediately after activity or be delayed by hours or even days.
- Recovery, if it occurs, can take days, weeks, months, or longer.
- A pathological low threshold for physical and mental fatigability (lack of endurance), which significantly reduces prior activity levels.

SYMPTOMS

A.- Neurological Dysfunction:

Neurocognitive deficits, significant pain, sleep disturbances, neurosensory, perceptual, and motor abnormalities, etc.

B.- Immune/Digestive/Genitourinary Dysfunction:

Flu-like symptoms, increased susceptibility to infections, digestive disorders, genitourinary dysfunction, hypersensitivities, etc.

C.- Dysfunction in Cellular Energy Metabolism and Ion Transport:

Cardiovascular and autonomic issues, respiratory problems, abnormal thermoregulatory responses, intolerance to extreme temperatures, etc.