

Comprehensive Symptom Guide of Myalgic Encephalomyelitis

Part #2

1. Overview of Myalgic Encephalomyelitis (M.E.)

Myalgic Encephalomyelitis (M.E.) is a distinct neurological disease recognized by the World Health Organization since 1969. It can occur in both epidemic and sporadic forms and is not the same as CFS or ME/CFS. Fatigue alone is not a defining feature.

M.E. is a multi-system disease primarily caused by post-encephalitic damage to the brainstem — a nerve center that controls vital bodily functions. This central nervous system (CNS) dysfunction is the main driver of the illness and explains the wide range of symptoms affecting multiple bodily systems.

Key characteristics:

- Sudden onset: Many patients can pinpoint the exact day and sometimes the hour they became ill.
- Neurological basis: The brain controls all vital functions, so dysfunction here affects nearly every system.
- Vascular and cardiac involvement: Secondary effects include low blood pressure, abnormal heart rate, and reduced blood volume.
- Multi-system impact: More than 60 symptoms have been documented, including neurological, cardiovascular, muscular, cognitive, immune, sensory, gastrointestinal, respiratory, and endocrine dysfunctions.

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2. Core Defining Feature: Post-Exertional Neuroimmune Exhaustion (PENE)

The hallmark of M.E. is Post-Exertional Neuroimmune Exhaustion (PENE) — a pathological inability to produce sufficient energy in response to physical, cognitive, or sensory activity.

Characteristics of PENE:

- Symptoms worsen after even minimal exertion, often with a delayed onset of 24–72 hours.
- Recovery can take days, weeks, or longer, and repeated overexertion can lead to disease progression or permanent harm.
- Limits are individual: Patients have a personal “energy envelope” that must be respected. Exceeding it triggers worsening of neurological, cognitive, cardiac, immune, muscular, and other symptoms.

- M.E. patients may function at 50% or less of their pre-illness capacity, and even routine tasks can cause relapse.
- Severe cases: Some patients have no safe activity limits and may be bedridden, highly sensitive to light, sound, or touch, and reliant on caregivers.

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3. Neurological & Cognitive Dysfunction

Neurological dysfunction is central to M.E. and affects memory, cognition, speech, sensory perception, coordination, and consciousness. Many symptoms fluctuate and worsen with exertion or sensory input.

Key symptoms include:

Memory & Cognitive Function:

- Difficulty forming new memories and recalling recent information.
- Problems with short-term and long-term memory recall, including facial recognition.
- Cognitive slowing, impaired concentration, and frequent need for mental micro-rests.
- Difficulty following step-by-step instructions, sequencing, multitasking, or learning new tasks.
- Loss of arithmetic skills (dyscalculia) and difficulty managing numbers or schedules.
- Reduced verbal and performance IQ (up to 20 points on average).

Speech & Language:

- Word-finding difficulty, incorrect word substitution, delayed speech comprehension.
- Writing difficulties, including agraphia (inability to write) and dyslexia-like symptoms.
- Difficulty understanding spoken or written language, especially in noisy environments.
- Speech may become slurred, stammered, or entirely lost in severe cases.

Perception & Sensory Processing:

- Spatial disorientation, poor coordination, and impaired proprioception.
- Vertigo, dizziness, and balance disturbances.
- Altered time perception or feeling “spaced out” or detached.
- Increased need for visual or multisensory cues to understand surroundings or conversation.

Neurological Episodes & Severe Dysfunction:

- Stroke-like episodes or transient amnesia.
- Seizure activity, including sensory storms or low-level seizures triggered by light, sound, or other stimuli.
- Severe cases: difficulty maintaining consciousness, coma-like episodes, or profound cognitive shutdown.

Emotional & Behavioral Effects:

- Emotional lability: mood swings, irritability, intense emotions, or emotional flattening.
- Anxiety, panic attacks, or depression often linked to physical symptom exacerbation.

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4. Autonomic & Cardiovascular Dysfunction

M.E. frequently affects the autonomic nervous system, leading to abnormal heart rate, blood pressure, and circulation. Symptoms often worsen with standing, exertion, or sensory stress.

Key symptoms:

- Heart rate irregularities: Tachycardia, bradycardia, palpitations, skipped or extra beats, arrhythmias, chest pressure or fluttering.
- Blood pressure instability: Low blood pressure (hypotension), especially when upright, or sudden drops causing blackouts; high blood pressure may occur with activity.
- Orthostatic intolerance: Postural Orthostatic Tachycardia Syndrome (POTS) or delayed POTS; Neurally Mediated Hypotension (NMH) causing blood to pool in extremities.
- Circulatory symptoms: Swelling (edema) of hands and feet, cold or blue extremities (Raynaud's phenomenon).
- Exacerbation with exertion: Symptoms worsen with standing, activity, or sensory stress, and lying down often provides relief.

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5. Immune System Dysfunction & Allergies

M.E. causes immune dysregulation, leaving patients more vulnerable to infections and hypersensitivities. Immune problems fluctuate with illness severity and exertion.

Key symptoms:

- Frequent infections: Recurrent colds, flu-like illness, urinary tract infections, shingles, fungal infections.

- Lymph node tenderness: Neck, armpits, elbows, and groin may be swollen or painful.
- Allergic and chemical sensitivities: Reactions to foods, drugs, perfumes, cleaning chemicals, plastics, or air pollutants.
- Food intolerances: New or worsening reactions to foods, additives, or alcohol.
- Immune fluctuation: Some patients may catch every infection around them; others may “never get sick” depending on disease stage.

Allergy-related symptoms can affect:

- Skin: Itching, rashes, flushing, hives, eczema.
- Eyes: Redness, watering, eyelid twitching.
- Ears: Pain, tinnitus, dizziness.
- Nose & throat: Congestion, sneezing, difficulty swallowing.
- Lungs: Shortness of breath, wheezing, coughing.
- Muscles & joints: Fatigue, pain, stiffness.

N• Cognition: Brain fog, anxiety, irritability, panic, depression.

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6. Endocrine & Metabolic Dysfunction

M.E. affects hormonal and metabolic regulation, leading to temperature instability, energy deficits, and other systemic problems.

Key symptoms:

- Thyroid & adrenal dysfunction: Secondary hypothyroidism, over- or under-active adrenal function, pituitary issues.
- Temperature dysregulation: Cold or hot flashes, sudden chills, low-grade fever, subnormal body temperature, night extremity hypothermia.
- Sweating abnormalities: Profuse sweating even when cold, night sweats, sour-smelling sweat.
- Weight changes: Rapid or unexplained weight gain or loss.
- Loss of adaptability to stress: Worsening of symptoms with physical, cognitive, or emotional stress due to endocrine/metabolic dysfunction.

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7. Muscular & Joint Dysfunction

M.E. affects muscles and joints through pain, weakness, stiffness, and delayed recovery.

Key muscular symptoms:

- Muscle weakness or paralysis: Muscles may function normally at first, but after even short use, they become weak or paralyzed for days to weeks. All muscles can be affected, including heart, eyes, and digestive muscles.
- Delayed recovery: Muscle recovery is pathologically slow; overuse can cause prolonged weakness and pain.
- Muscle pain (myalgia): Sharp, shooting, burning, or aching pain; sometimes described as being beaten or stabbed.
- Muscle spasms and tremors: Hands, feet, neck, or other muscles may spasm painfully; visible twitches or tremors may occur.
- Loss of facial expression: Facial muscles may become slack or weak.
- Paresthesias: Tingling, numbness, or burning sensations in muscles or extremities.
- Muscle atrophy: In some cases, visible shrinkage of specific muscles.

Key joint symptoms:

- Widespread joint pain: Often affects knees, ankles, hips, elbows, and fingers.
- Stiffness (“gelling”): Joints may stiffen after holding positions, waking, or with weather changes.
- Gait and movement difficulties: Trouble walking or maintaining balance; tandem gait may be impaired.

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8. Sensory Dysfunction (Eyes, Ears, Vestibular)

M.E. patients experience heightened sensitivity and abnormal responses to sensory input.

Visual symptoms:

- Photophobia (light sensitivity), double vision, blurred or wavy vision.
- Nystagmus (involuntary eye movement), floaters, or scratchy/dry eyes.
- Difficulty focusing, depth perception loss, reading or writing challenges, color perception disturbances.

Auditory symptoms:

- Hyperacusis (intolerance to normal sound volume, especially high frequencies).
- Tinnitus (ringing, buzzing, clicking, humming).
- Hearing loss or muffled hearing; trouble distinguishing sounds.
- Ear pain, deep itching, or swelling of nasal passages.

Vestibular symptoms:

- Vertigo or spinning sensations, imbalance, acute ataxia (severe coordination problems).
- Motion sensitivity affecting walking, reading, or watching screens.

Speech & communication:

- Weak, hoarse, slurred, or lost speech.
- Difficulty pronouncing words, forming sentences, or recalling words.
- Speech comprehension problems, often worse in noisy or multi-speaker environments.

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9. Gastrointestinal Dysfunction

M.E. frequently disrupts digestion, swallowing, and appetite.

Key symptoms:

- Difficulty swallowing or painful swallowing (dysphagia).
- Oesophageal spasms or reflux (heartburn), sometimes radiating to chest/back.
- Nausea, vomiting, bloating, abdominal pain, cramping, diarrhea, or constipation.
- Food intolerances, allergies, or bizarre taste/smell sensations.
- Gallbladder or liver pain; alcohol intolerance is common.
- Strong food cravings or loss of appetite; poor fat tolerance.

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10. Respiratory Dysfunction

Breathing can be affected both at rest and with exertion.

Key symptoms:

- Shortness of breath, air hunger, or difficulty breathing (dyspnea).
- Erratic breathing patterns; sudden breathlessness while resting or sleeping.

- Persistent cough or wheezing; exacerbated by exertion or infection.

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11. Sleep Dysfunction

Sleep is often non-restorative and irregular, with multiple stages of disruption.

Key symptoms:

- Unrefreshing sleep, waking more exhausted than before bed.
- Difficulty initiating or maintaining sleep (fragmented sleep).
- Very light sleep; lack of deep-stage sleep.
- Hypersomnia (excessive sleep), especially in acute or pediatric cases.
- Circadian rhythm disruption, reversed sleep-wake cycles.
- Sleep paralysis, dysania (difficulty rising from bed), or transient immobility on waking.
- Intense or vivid dreams, nightmares, or lack of dreams.
- Night extremity hypothermia or profuse sweating during sleep.

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12. Pain

M.E. causes widespread, varied, and often severe pain, which can be muscular, joint, or neurological in origin.

Key pain types:

- Muscle pain: Dull, aching, bruised feeling or sharp, spike-like pains after muscle use; delayed onset lasting days to weeks.
- Joint pain: Aching, stiffness (“gelling”), worsened by position or weather changes.
- Head pain: New or unusual headaches, occipital pain, retro-orbital pain, sinus or tension headaches, hypoglycemia-related headaches.
- Neuropathic/nerve pain: Neuralgia, causalgia, urogenital pain, abdominal pain, periarticular pain.
- Pain sensitivity: Allodynia—pain triggered by stimuli not normally painful (e.g., touch, sheets, clothing).

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13. Reproductive Dysfunction

M.E. may affect reproductive and sexual health.

Key symptoms:

- Menstrual irregularities: shorter, longer, lighter, or missing periods; symptoms may worsen before or during menstruation.
- Lowered libido.
- Impotence in men.
- Worsened PMS or endometriosis-related pain.

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14. Urinary Dysfunction

Urinary symptoms are common due to autonomic and neurological involvement.

Key symptoms:

- Increased frequency or urgency.
- Painful or burning urination (dysuria).
- Difficulty passing urine or incontinence.
- Nocturia (excessive nighttime urination).

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15. Weather & Environmental Sensitivity

M.E. patients are highly sensitive to environmental changes.

Key symptoms:

- Worsened symptoms with heat, cold, humidity, or rapid weather changes.
- Migraines, irritability, insomnia, or feeling “off” before weather shifts.
- Increased muscle pain or stiffness with barometric changes.

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16. Weight Changes

M.E. can lead to rapid or unexplained weight fluctuations.

Key symptoms:

- Weight gain independent of diet.
- Weight loss despite adequate food intake, more common in children and teenagers.

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17. Late Effects of M.E.

Long-term M.E. can result in persistent multi-system problems, even in patients who have been clinically stable.

Key late effects:

- Overwhelming fatigue (physical and mental).
- Cognitive disturbances and memory issues.
- Muscular and joint pain; muscle weakness and wasting.
- Respiratory difficulties, swallowing problems, and voice production issues.
- Episodes of hypothermia, low blood pressure, or breathlessness.

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18. M.E. Fatalities

Deaths are uncommon but can occur, usually from:

- Organ failure (cardiac or pancreatic).
- Secondary infections.
- Respiratory failure.

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19. Co-Morbid Conditions

Some conditions frequently occur alongside M.E.:

- Mitral Valve Prolapse, viral myocarditis, pericarditis.
- Depression, irritable bowel syndrome, Raynaud's phenomenon.
- Shingles, fungal infections, multiple chemical sensitivity.
- Carpal tunnel syndrome, piriformis syndrome, fibromyalgia.
- Temporomandibular joint syndrome (TMJ), Hashimoto's thyroiditis, sicca syndrome.
- Endometriosis, dysmenorrhea, severe PMS, migraines, restless legs syndrome (RLS).

*Sleep apnea, irritable bladder, cystitis, prostatitis, Sjogren's syndrome.

Part 1:

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