The refusal of doctors to treat or even recognize patients with Myalgic Encephalomyelitis (ME) has deep historical, political, and systemic roots. This refusal has left many with ME without adequate medical care, leading patients to rely on self-education, peer support, and rare specialists who acknowledge ME as the severe neurological disease it is.

Historical Misclassification

* In the 1950s–1980s, outbreaks of ME (often post-viral, with neurological signs) were documented, but psychiatry gained influence in reclassifying ME as a psychosomatic fatigue disorder.

* The 1988 U.S. “CFS” definition reframed ME as “chronic fatigue,” erasing encephalomyelitis from recognition and blurring it with general tiredness.

* Once coded as CFS, ME lost its neurological disease status in medical education and in practice.

2. Medical Training Gap

* ME is rarely included in medical school curricula.

* Textbooks either omit ME or present it under “CFS,” described vaguely as “medically unexplained fatigue.”

* This leaves new doctors without knowledge of the neurological, immunological, and vascular evidence in ME.

3. Psychiatric Dominance

* Powerful psychiatric schools (especially in the UK, but echoed internationally) promoted the theory that ME is a form of somatization, deconditioning, or false illness beliefs.

* Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET) were promoted as “evidence-based” treatments, despite patient harm and contrary biomedical findings.

* Doctors trained under this model often dismiss ME patients as psychosomatic.

4. Insurance and Policy Pressures

* Acknowledging ME as an organic, incurable, and disabling neurological disease would increase pressure on healthcare systems, insurers, and disability programs.

* The conflation with “CFS” allows governments and insurers to minimize costs, because fatigue can be classified as temporary, treatable, or psychological.

* Doctors are influenced by these structures: refusing or minimizing ME avoids bureaucratic and financial challenges.

5. Diagnostic Uncertainty

* There is no simple lab test for ME. Diagnosis requires clinical acumen and exclusion of other causes — something many physicians are uncomfortable with or too rushed to undertake.

* Doctors often default to: “We don’t know what this is, so it must be psychological.”

* The lack of official diagnostic training reinforces avoidance.

6. Fear of Complexity and Liability

* ME patients often have multisystem dysfunction: neurological, cardiovascular, immune, metabolic.

* This complexity overwhelms doctors working in fragmented, specialty-based healthcare systems.

* Some refuse patients because they fear they can’t “fix” them, or they’re afraid of being challenged when patients know more than they do.

7. Stigma and Patient Blame

* Because ME patients are often bedbound, sensitive to light/sound, and unable to attend frequent appointments, doctors label them as “non-compliant” or “difficult.”

* When standard tests look normal, doctors may interpret symptoms as exaggeration.

* Patients who challenge GET/CBT recommendations are sometimes written off as hostile or “anti-psychiatry.”

8. Gender Bias

* ME disproportionately affects women. Historically, women with complex unexplained illnesses have been dismissed as “hysterical” or “emotional.”

* This bias still shapes medical encounters today, leading to dismissal instead of investigation.

9. Scientific Gatekeeping

* Biomedical researchers have produced strong evidence for ME (neuroinflammation, hypoperfusion, immune abnormalities, mitochondrial dysfunction).

* However, because funding is scarce and psychiatric models dominate official guidelines, many doctors never see this research.

* Without “approved” biomarkers, they claim the disease “doesn’t exist” or isn’t “real.”

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ME isn't the only disease that's been dismissed, psychologized, and mistreated before later being recognized as a serious organic illness. Looking at these parallels is very powerful, because it shows a repeating historical pattern in medicine.

Multiple Sclerosis (MS)

* Early history: In the late 19th and early 20th centuries, many physicians believed MS was caused by hysteria, neurasthenia, or neurosis — particularly because it often affected young women.

* Dismissal: Patients with muscle weakness, paralysis, vision problems, and fatigue were often told their symptoms were "in the mind."

* Shift: Only once neuropathology and later imaging (MRI) showed demyelination was MS accepted as a neurological disease. Parallel with ME: both have neurological, relapsing symptoms that were dismissed as psychological for decades.

2. Epilepsy

* Ancient view: Epilepsy was considered a form of possession or madness for centuries.

* 19th century: Even in medical circles, seizures were often classified as psychiatric hysteria.

* Modern shift: EEG and neurophysiology proved its electrical basis in the brain. Parallel with ME: neurological dysfunction without visible lesion led to dismissal until better tools emerged.

3. Parkinson's Disease

* Before James Parkinson's 1817 description, patients with tremor, rigidity, and gait disturbances were often thought to have psychiatric illness, "shaking palsy," or age-related frailty.

* Patients were dismissed as senile or anxious until neuropathology identified degeneration of dopaminergic neurons.

4. Systemic Lupus Erythematosus (SLE)

* Lupus often presents with fatigue, pain, rashes, neurological symptoms, and shifting clinical signs.

* For decades, many women with lupus were told they were hypochondriacs or had "psychosomatic complaints."

* It wasn't until immunology advanced that lupus was recognized as an autoimmune disease. Parallel with ME: fluctuating multisystem illness, often dismissed in women, labeled as psychosomatic.

5. Fibromyalgia

* Long considered a psychosomatic or somatoform disorder.

* Patients were told their widespread pain was stress-related or "all in the head."

* Only in the last two decades has fibromyalgia gained recognition as a disorder of central pain processing with distinct neurobiological features.

6. Asthma

* Before the 20th century, asthma was thought to be a nervous disorder caused by anxiety.

* Children with asthma were often labeled "weak" or "neurotic."

* Recognition of airway inflammation and allergic triggers reframed it as a chronic organic disease.

7. Peptic Ulcers

* For most of the 20th century, ulcers were blamed on stress and personality.

* Patients were told they had "type A personalities" or nervous stomachs.

* Discovery of Helicobacter pylori in the 1980s overturned this, showing ulcers are bacterial in origin.

8. Endometriosis

* Women with pelvic pain were told they were exaggerating, unstable, or suffering from "hysteria."

* Even today, diagnosis is often delayed by 7–10 years because of dismissal.

* Now recognized as a gynecological disease involving ectopic endometrial tissue and systemic inflammation.

9. Lyme Disease (and Post-Treatment Lyme)

* Patients with neurological or systemic symptoms after tick exposure were often dismissed as hypochondriacs or anxious.

* Chronic/post-treatment Lyme remains controversial, with some patients still denied care, echoing the ME experience.

Common Pattern

1. Disease has invisible pathology (no biomarker yet, or fluctuating symptoms).

2. Patients are often women, reinforcing gendered dismissal.

3. Labeled psychological or hysterical.

4. Only after biomarkers or imaging become available does the medical establishment shift to recognition.

5. By then, decades of patient suffering, neglect, and abuse have occurred.

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These references illustrate the pattern of dismissal across different conditions — just like ME: first labeled as psychological or stress-related, then later vindicated by biomedical discovery.

Picture comes from here: https://me-pedia.org/.../File:Individuals_referred_by...

Multiple Sclerosis (MS)

* Murray TJ. The history of multiple sclerosis: From the age of description to the age of molecular biology. Neurol Clin. 2005;23(1):1–15. Notes how MS was long considered a type of hysteria or psychosomatic weakness before neuropathology proved otherwise.

Epilepsy

* Temkin O. The Falling Sickness: A History of Epilepsy from the Greeks to the Beginnings of Modern Neurology.Johns Hopkins University Press; 1994. Classic historical account of epilepsy as “madness” or hysteria until EEG showed abnormal brain activity.

Systemic Lupus Erythematosus (SLE)

* Schur PH. Historical perspective of systemic lupus erythematosus. In: Lahita RG, et al. (eds.) Systemic Lupus Erythematosus. 5th ed. Elsevier; 2011. Describes how lupus patients (mostly women) were dismissed as neurotic before autoimmunity was understood.

Asthma

* Jackson M. Asthma: The Biography. Oxford University Press; 2009. Shows how asthma was once considered a nervous disorder caused by anxiety before recognition of airway inflammation.

Peptic Ulcer

* Marshall BJ, Warren JR. Unidentified curved bacilli in the stomach of patients with gastritis and peptic ulceration.Lancet. 1984;323(8390):1311–1315. Landmark paper proving ulcers were bacterial, not “stress-induced.”

Endometriosis

* Seear K. The etiquette of endometriosis: Stigmatisation, menstrual concealment and the diagnostic delay. Soc Sci Med. 2009;69(8):1220–1227. Documents how women's pain was dismissed as psychological or "hysterical," leading to delayed diagnosis.

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