OVERLY BROAD DIAGNOSTIC CRITERIA: MASKING BIOMEDICAL EVIDENCE

The conflation of ME with CFS has further obscured its biomedical reality. Throughout the 1990s and 2000s, studies often relied on overly broad diagnostic criteria, such as the Oxford or Fukuda criteria. These definitions classified CFS broadly, **failing to specifically identify ME patients and instead including individuals with idiopathic chronic fatigue or psychiatric fatigue disorders.** As a result, the study populations became diluted, masking the biological abnormalities characteristic of true ME. This misclassification led to erroneous conclusions that ME lacks consistent biomarkers, thereby reinforcing the false psychological narrative.

By failing to properly select patients with hallmark ME features—such as post-exertional malaise and autonomic dysfunction—these flawed studies distorted the scientific and medical understanding of the disease. This, in turn, fueled ongoing medical scepticism and hindered recognition of ME as a distinct biomedical condition.

THE HARMS OF GET AND THE BIOMEDICAL EVIDENCE OF ME

The widespread promotion of graded exercise therapy (GET) caused profound harm to ME patients. Despite patient surveys and biomedical studies demonstrating that GET worsens symptoms and leads to severe relapses, it remained a recommended treatment for years and, despite being removed from treatment recommendations in the revised NICE Guideline 206 in 2021, it is still promoted under different guises, despite the evidence of serious harm it inflicts on ME patients, reflecting the profession's resistance to updating harmful practices.

FATALITIES AND THE CONSEQUENCES OF MEDICAL NEGLECT

The widespread disbelief in Myalgic Encephalomyelitis (ME) has led to tragic and fatal outcomes. Patients with severe ME are often left bedbound, malnourished, and in considerable pain—yet they are frequently denied appropriate medical care because of medical disbelief. Some have died from neglect or complications of the disease, their deaths wrongly attributed to eating disorders or deemed self-inflicted. This misrepresentation not only obscures the true cause of death but also perpetuates harmful stigmas, leaving future patients vulnerable to the same mistreatment.

A LONG ROAD TO RECOGNITION

The medical community's dismissal of ME is not due to a lack of biomedical evidence but rather the result of entrenched misinformation, corporate influence, and professional bias. Key events such as the Belfast meeting, the involvement of insurance companies like Unum, and the flawed PACE trial played significant roles in promoting medical gaslighting and downplaying the severity of ME. As a result, thousands of ME sufferers continue to endure debilitating symptoms without proper care. Many are subjected to harmful, outdated treatments and denied validation of their illness. Tragically, some lose their lives due to the medical system's failure to recognise the physical reality of ME. However, as biomedical research increasingly reveals the disease's physiological underpinnings, hope remains that the medical establishment will abandon discredited models and finally acknowledge ME as the devastating, life-threatening illness it is.

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management, NICE guideline [NG206], published 29 October 2021.

ME: A History of Misinformation, Bias, and Neglect

BY JENNY WILSON
Associate Member of Doctors with ME

Myalgic Encephalomyelitis (ME), is a complex, potentially fatal, multi-system disease affecting millions worldwide. Despite decades of biomedical evidence highlighting cardiovascular, immunological, and neurological abnormalities, many doctors still dismiss ME as a psychological or psychosomatic condition. This pervasive disbelief has led to widespread mistreatment, neglect, and iatrogenic harm, with tragic and even fatal consequences for patients.

The reasons behind this entrenched disbelief stem from a combination of historical misinformation, corporate influence, flawed research, and career-driven biases. It is crucial to understand the key factors that have shaped and sustained the medical profession's dangerous misunderstanding of ME.

THE BELFAST MEETING OF 1992: THE DELIBERATE ERADICATION OF ME

The dismissal of ME was significantly influenced by the 1992 Belfast conference, "Eradicating Myalgic Encephalomyelitis." Sponsored by Pfizer Invicta Pharmaceuticals, the meeting offered a platform for members of the Wessely School to proclaim their clear objective: to ***reclassify*** ME as a behavioural/mental disorder. During the event—and in the years that followed—attendees promoted the narrative that ME was not a distinct neuroimmune disease but rather a psychosomatic condition driven by maladaptive illness beliefs

and physical deconditioning. This stance disregarded a growing body of biomedical evidence demonstrating immune dysfunction, cardiovascular irregularities, autoimmunity, and neurological inflammation, effectively denying the biological reality of the disease.

The strategy involved rebranding ME under the CFS label, which categorised it as a mental health condition rather than a neuroimmune disease; promoting the term CFS/ME to blur the distinction between the two conditions. Erasing the ME label when expedient left the illness solely in the mental and behavioural category; and encouraged the use of cognitive behavioural therapy (CBT) and graded exercise therapy (GET) as primary treatments, despite the lack of evidence for their efficacy and the known harm they cause.

CORPORATE AND GOVERNMENT INFLUENCE: PRIORITISING PROFITS OVER PATIENTS

Insurance companies, particularly UnumProvident (now Unum), played a significant role in shaping the narrative around ME. Enabled by their psychiatric advisors, insurers framed ME as a psychological disorder, ***and therefore could avoid payouts, as mental health was exempt from permanent cover.***

The two key determining factors were:

- **Lobbying against ME's biomedical classification:** Permanent insurance companies and their medical advisors exerted influence to prevent ME from being recognised as a neurological disease, despite its official classification as such in the WHO guidelines since 1969.
- **Government complicity:** Governments, concerned with the financial implications of recognising ME as a disabling physical illness, aligned with insurance companies. By endorsing the biopsychosocial model—which largely ignored biological factors—governments avoided large-

Deliberate misclassification served both financial and political interests ***by reducing the burden on insurance companies and government welfare programs.***

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scale costs for disability benefits and biomedical research.

The financial incentives to discredit ME ensured that patients were denied the support they needed, forcing many into poverty and worsening their suffering.

FLAWED RESEARCH AND THE PACE TRIAL SCANDAL

The 2011 PACE trial is one of the most infamous examples of flawed research influencing ME treatment guidelines. The study, funded partly by the DWP, claimed that CBT and GET were effective treatments for ME. However, the trial was later discredited due to:

- **Methodological flaws:** The researchers altered outcome measures mid-trial, making it easier for patients to be classified as "improved" without genuine recovery. The inclusion criteria were far too broad so many probably did not have ME.
- **Data manipulation:** By switching the criteria for improvement, the authors exaggerated the recovery statistics and the benefits of CBT and GET.
- **Patient harm:** Subsequent patient surveys revealed that GET exacerbated symptoms and caused severe relapses in many ME patients.

Despite being widely discredited, the PACE trial's influence persisted for years, reinforcing medical disbelief and encouraging the continued use of harmful treatments.

CAREER INTERESTS AND THE PROTECTION OF REPUTATIONS

Doctors and researchers who built their careers on the psychosomatic model have a vested interest in defending it, even as biomedical evidence proves them wrong. Admitting that ME is a physical disease would invalidate decades of their research and expose them to scrutiny for promoting ineffective—and harmful—treatments and, perhaps, accusations of scientific misconduct.

Career-driven biases prevent many physicians from re-evaluating their stance, even in the face of mounting peer-reviewed evidence revealing the biological underpinnings of ME, including:

- **Cardiovascular dysfunction:** Hypovolemia, orthostatic intolerance, impaired blood flow regulation, severe damage to the endothelium of the blood vessels, and cellular ischemia.
- **Immunological abnormalities:** Chronic immune activation, abnormal cytokine profiles, and viral reactivation.
- **Neurological damage:** Brain inflammation, reduced cerebral blood flow, cognitive impairments, and inflamed dorsal root ganglia.

There is impaired oxygen delivery to muscles, oxidative stress, impaired HPA function, shrunken adrenals, leaky gut, and much more.

Medical history reveals that it is a common failing for doctors to resist new scientific discoveries, clinging to outdated models even when confronted with irrefutable evidence. This is neatly referred to as the 'Semmelweis Reflex'.