

# Chronic Fatigue Syndrome: A Moral **Exploration of Illness and Accountability**

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#### Abstract

Chronic fatigue syndrome (CFS) is a complex and often debilitating condition characterized by persistent fatigue accompanied by a variety of additional symptoms that often include muscle pain, cognitive impairment, and post-exertional malaise. Despite affecting millions worldwide, CFS remains poorly understood and frequently stigmatized. This paper explores historical and contemporary social perceptions of CFS, framing them within broader discussions of health, morality, and personal responsibility. By drawing on parallels to conditions like neurasthenia and hysteria, this research examines how societal values—particularly those shaped by the Protestant ethic and eugenics—have influenced perceptions of illness and morality. It highlights how attributing unverifiable illnesses to personal responsibility affects societal attitudes toward those with CFS. Additionally, this paper explores the gendered dimensions of CFS, historically linked to women yet increasingly recognized in men. Recent developments, including the condition's overlap with long COVID-19, emphasize the ongoing need for research and improved treatment strategies.

## Keywords

Chronic fatigue symptom, Myalgic Encephalomyelitis, Post-viral fatigue syndrome, Post-exertional malaise, Long COVID, Psychosomatic illness, Functional somatic syndromes, Neurological disorders, Immune dysfunction, Psychogenic explanations of illness



Chronic fatigue syndrome (CFS), also known as Myalgic Encephalomyelitis (ME), is a complex and often debilitating condition marked by persistent, unexplained, or relapsing fatigue. This fatigue is of new or definite onset (not lifelong), unrelated to ongoing exertion, not significantly relieved by rest, and lasts for at least six months. In order to be diagnosed, the condition must also result in a substantial decline in occupational, educational, social, or personal activities. In addition, at least four of the following symptoms must occur simultaneously: cognitive difficulties (such as memory or concentration issues), sore throat, tender lymph nodes, muscle pain, joint pain without swelling or redness, headaches that are new in pattern or severity, unrefreshing sleep, and post-exertional malaise (PEM) (Graves et al., 2024). PEM, a hallmark of CFS, involves a worsening of symptoms following minimal physical or mental exertion, with effects that can persist for hours, days, or even weeks beyond the activity that triggered it (Friedman, 2019, p. 2). While there is evidence that CFS often manifests after an acute infection such as mononucleosis, Lyme disease, or Q fever, its exact cause remains unclear, as no consistent infectious agent has been identified. (Evengård et al., 1999, p. 458). Despite affecting millions worldwide, CFS remains poorly understood, and those living with the condition frequently face skepticism from both society and the healthcare system.

The classification and interpretation of CFS have long been contentious, particularly concerning its origins—whether it is biological or psychological. This debate goes back to at least the late 19th century, when a similar condition was first identified as a distinct disorder. Despite ongoing recognition and research into its causes, CFS and related conditions have remained stigmatized. This enduring stigma stems from deep-seated societal values and ideologies that shape perceptions of health (Crawford, 1997, p. 404). In his 1997 article, "Health as a Meaningful Social Practice," Robert Crawford argues that health is more than a biological or medical concept—it is also a symbolic and ideological construct that both reflects and reinforces societal values, identities, and power structures (p. 404). The way health and illness are communicated influences perceptions of character and shapes broader understandings of a moral and virtuous existence (Arney and Bergen, 1984, as cited in Crawford, 1997, p. 404). Thus, to fully grasp health practices and their societal impact, one must examine historical and contemporary knowledge, medical practices, and the political and economic forces that shape health discourse (Crawford, 1997, p. 404).

Historical records spanning centuries document the existence of disorders with symptoms resembling those of CFS and reflect society's evolving struggle to understand and contextualize such conditions within a broader framework. In the 18th century, Scottish physician George Chyene described a widespread nervous disorder in England that was characterized by anxiety, depression, and hypochondria. Cheyne attributed these illnesses to the excesses of modern English life, highlighting how social behaviours and values could worsen health problems. He particularly noted the detrimental impact of overindulgence in food, alcohol, and fashionable lifestyles, which often included late nights and wanton behaviour (Porter, 2001, p. 33). This perspective laid the groundwork for future discussions linking health to moral responsibility.

In 1869, American neurologist George Beard introduced the term 'neurasthenia' to describe a state of nervous exhaustion that had become prevalent in the industrial era (Porter, 2001, p. 39). Beard linked neurasthenia to the overwhelming demands placed on the nervous system by rapid modernization, citing factors such as urbanization, immigration, mechanization, and advances in communication (Porter, 2001, p. 39). Neurasthenia was characterized by a cluster of symptoms, including profound fatigue, difficulty concentrating, irritability, headaches, insomnia, phobias, nightmares, digestive issues, depression, anxiety, impotence, and heart palpitations (Porter, 2001, p. 39). Beard observed that the condition primarily affected the affluent, who were heavily involved in the pressures of modern life, particularly through mentally demanding education and careers. However, Beard also noted a high prevalence of neurasthenia among upper-class women, who, since the Age of Enlightenment, had increasingly pursued intellectual activities. These women were believed to experience heightened stress due to their increased cognitive exertion compared to their rural and lower-class counterparts (Porter, 2001, p. 39). Despite its widespread occurrence and debilitating symptoms, in an era that had fully embraced science and medicine through a lens of reason, observation, and empirical evidence, neurasthenia struggled to gain full recognition as a legitimate illness within the medical community. Instead, it was frequently dismissed as hysteria, weakness, malingering, or feigned illness (Evengård et al., 1999, p. 455).

During this period, the concept of 'hysteria' loomed large in medical discourse, commonly attributing a wide range of physical and psychological symptoms to supposed dysfunctions of the uterus or ovaries in women, but also to sexual frustration and masturbation in men (Marland, 2001, p. 22). Hysteria was not merely considered a medical condition; it was also deeply tied to

ideas of moral decline, emotional instability, and irrationality (Marland, 2001, p. 29). Those diagnosed with hysteria were often seen as lacking willpower, self-discipline, and moral fortitude, with their symptoms interpreted as a failure to meet social expectations and responsibilities (Marland, 2001, p. 29). Moreover, individuals who reported symptoms that could not be objectively verified were frequently met with suspicion, and their illness was often dismissed as malingering—an attempt to avoid work or gain sympathy (Marland, 2001, p. 29). These prevailing attitudes reinforced the belief that conditions like neurasthenia were not genuine illnesses, but rather signs of laziness, self-indulgence, or deceit, reflecting broader societal values regarding health, morality, and personal responsibility.

Societal beliefs linking illness to morality were deeply influenced by the Protestant work ethic, a concept extensively explored and analyzed by sociologist Max Weber in *The Protestant Ethic and the Spirit of Capitalism* (1905). Grounded in Protestant Christian values, particularly those of Calvinism, this ethic emphasized productivity, resilience, diligence, and piety as expressions of devotion to God. It promoted individualism, self-discipline, and the notion that economic success was a testament to one's moral virtue, an essential factor in maintaining social respectability (Crawford, 1997, p. 405). As the early 20th century progressed, a growing appreciation for leisure appeared to challenge the Protestant ethic (Crawford, 1997, p. 405). However, rather than rejecting traditional values, leisure was redefined to align with them. Leisure time was not meant for 'slacking,' but for fostering physical vitality, rejuvenation, and self-improvement (Crawford, 1997, p. 405). It was believed that failure to use leisure time productively would lead to negative consequences (Crawford, 1997, p. 405). These deeply ingrained ideologies continue to significantly shape societal views on illnesses like CFS, often linking the conditions to personal failings.

In the late 19th and early 20th centuries, the rise of eugenics and shifting attitudes toward work, leisure, and health significantly influenced societal perceptions of illness and morality. Eugenicists warned that civilization was at risk of decline due to the unchecked reproduction of the unfit and unhealthy, framing genetic weakness as a primary threat to societal progress (Crawford, 1997, p. 406). This perspective was reinforced by theories suggesting that nervous collapse could be linked to hereditary deficiencies in physical capacity (Schofield, 1902, p. 102). One such theorist was British physician Alfred T. Schofield, who argued that functional nerve diseases affected individuals across all social classes, not just the affluent (Schofield, 1902, p.

102). In his 1903 work, *Nerves in Disorder: A Plea for Rational Treatment*, Schofield emphasized the increasing strain on the nervous system in an era where financial success depended more on mental exertion than physical labour. He wrote, "Money now is almost exclusively made at the expense of the wear-and-tear of nerve, as contrasted with muscle tissue; and it is a matter of ever-increasing importance to keep the money-making machine, the brain and the mind, at the highest productive pitch—in short, in a state of perfect health" (p. 4).

Eugenics fueled anxieties about an impending epidemic of hereditary degeneration, warning of "a reproductive triumph of lower types who would physically, mentally, and morally weaken and eventually destroy the social body" (Crawford, 1997, p. 406). While often associated with Nazi Germany, eugenics was widely accepted and institutionalized across many nations from the late 19th century to the mid-20th century. Canada, the United States, the United Kingdom, and several European nations implemented eugenics-based policies aimed at discouraging or preventing reproduction among those deemed 'unfit.' During this era, health and physical fitness were regarded as essential to societal progress. Exercise and sport were promoted as critical tools for strengthening the individual body and ensuring the human race's competitive edge (Crawford, 1997, p. 407). Those who failed to prioritize their health were seen as neglecting both their personal duty to self-improvement and their broader social responsibility to uphold health principles for the collective good (Crawford, 1997, p. 407).

Although eugenics was eventually discredited as pseudoscience by the scientific community (Wilson, 2024) and the influence of Christianity has waned in the Western world, deeply rooted ideologies continue to shape societal views of bodies deemed wasteful, unproductive, and non-donating to the greater social good. This condemnation is apparent in the way fatigue is perceived, often linked to personal moral failings and associated with slovenliness, one of the seven capital vices (Hardy, 2022, p. 43-44). Rather than eliciting sympathy, fatigue is frequently regarded as a physical manifestation of an individual's failure to uphold moral responsibility—namely, the duty to maintain one's health in order to remain productive (Radley & Billing, 1996, p. 221). These historical perspectives underscore the moral implications of CFS and how societal values and ideologies continue to influence the perception of illness. By framing health in moral terms, society often stigmatizes those with conditions like CFS, attributing their illness to a lack of self-discipline or personal responsibility. Understanding

these deeply ingrained beliefs is crucial for addressing the stigma and improving the lives of those affected by CFS.

While Beard had identified a widespread disorder resembling CFS in the mid-19th century, his hypothesis had been dismissed by his peers. They had rejected the notion that it could be a nervous system disorder caused by excessive mental activity, instead attributing the disorder to a mental condition, such as hysteria or a moral failing, such as a reluctance to work. However, as similar outbreaks were reported over time, the idea of CFS as a biological disease of the nervous system began to be reconsidered, with evidence suggesting that it could be contagious. One such outbreak occurred at Los Angeles County Hospital in 1934, and another was documented by British physician Edward Acheson in 1956 (Evengård et al., 1999, p. 458-459). Acheson coined the term Myalgic Encephalomyelitis (ME) to describe a neurological illness that affected both staff and patients at London's Royal Free Hospital in 1955 (Evengård et al., 1999, p. 458-459). Symptoms included severe fatigue, muscle weakness, pain, sensory disturbances, memory loss, and emotional instability (Evengård et al., 1999, p. 462). Acheson theorized that these symptoms were the result of inflammation of the brain and spinal cord (encephalomyelitis) that had been triggered by an unidentified infectious agent (Evengård et al., 1999, p. 462) Acheson also noted that some patients had experienced similar episodes in the past, suggesting a potential chronic or recurrent condition (Evengård et al., 1999, p. 462).

ME was not widely accepted as a legitimate diagnosis within the medical community. Critics of Acheson's work argued that there was no evidence of inflammation or infection in the nervous system (Evengård et al., 1999, p. 462). In 1970, psychiatrists Colin Peter McEvedy and Alfred William Beard revisited the 1956 outbreak at the Royal Free Hospital and concluded that it was a case of mass hysteria. As part of their reasoning, they pointed to the higher incidence of the illness among females compared to males (McEvedy & Beard, 1970, p. 7). This reinterpretation mirrored the skepticism that had surrounded the concept of neurasthenia a century earlier (Evengård et al., 1999, p. 462), which also noted a higher prevalence amongst women. Other psychiatrists suggested alternative explanations, such as conversion disorder (a condition in which a person has neurological symptoms—like paralysis or blindness—with no physiological cause) or somatoform disorder (a mental health condition in which a person feels highly distressed or anxious about physical symptoms that are not traceable to a physical cause).

These theories proposed that ME might be rooted in psychological distress rather than organic disease (Evengård et al., 1999, p. 462).

McEvedy and Beard's reassessment of the Royal Free Hospital outbreak coincided with a significant cultural shift in the mid-1970s, when health issues and their solutions were increasingly viewed through the lens of individual responsibility and control (Crawford, 1997, p. 408). This emphasis on personal accountability for health resonated with an individualistic culture that had once embraced eugenics and continued to associate hard work with moral integrity (Crawford, 1997, p. 408). This mindset was instrumental in the rise and normalization of neoliberal ideals, which emphasized personal responsibility, self-reliance, and minimal government intervention. By framing health as a personal matter, this perspective both reflected and reinforced neoliberal values, embedding them more firmly into the social ethos.

In the 1980s, the focus on health broadened to include not just physical well-being but also mental and spiritual wellness (Crawford, 1997, p. 410). This holistic view of health introduced an even wider moralization, where failing to achieve—or at least strive for—health was often seen as a failure to fully embrace life, understand one's emotions, or appreciate spiritual aspects. And when discussions about health are linked to personal responsibility, it is common to encounter views like those expressed by Canadian author, academic, and sometime politician Michael Ignatieff, who in 1988, stated, "We not only get the diseases we deserve: we get the diseases we want" (Ignatieff, 1988, p.29 as cited in Crawford, 1997, p. 411). Such rhetoric not only provides an opportunity for self-congratulation on the state of a person's good health but also offers an opportunity for moral judgment of those experiencing poor health, with little consideration for health matters outside a person's control. Therefore, it is important to critically examine the societal beliefs about health and the implications for those who do not experience good health or fail to conform to the dominant health ideals of the time.

In the late 1980s, another outbreak of a condition resembling CFS/ME occurred in the Lake Tahoe/Incline Village area of Nevada (Evengård et al., 1999, p. 458-459) and drew significant media attention. The illness was dubbed 'yuppie flu,' a term reflecting the perception that it primarily afflicted middle-to-upper-class professionals ("Yuppie Flu," 1989). Discussions surrounding the condition often extended beyond medical explanations, suggesting that these young professionals, who were often characterized by their fashionable lifestyle, materialism,

and financial success, were responsible for their own illness and attributed the disorder to their relentless drive in an ambition-fueled culture (Hunt, 2018, p. 175).

This period coincided with the second wave of feminism, which is largely agreed to span from the early 1960s to the early 1980s. Amid this wave, social roles of women were evolving, and many women were juggling multiple responsibilities, including careers, marriage, and parenthood. Media narratives, such as the one presented by Dr. Howard Seiden in a 1987 Toronto Star article, often suggested that women's attempts to 'have it all' were the root of their illness. Seiden's article presents a fictional medical case—implied to reflect a broader trend—of a woman seeking advice from multiple experts and exploring alternative therapies to combat her overwhelming fatigue. When doctors recommend that she slow down, she dismisses their advice and instead pursues alternative perspectives. Seiden goes on:

And, when one seeks, it comes to pass that one finds... Could a new or recurrent infection with EBV [Epstein-Barr Virus] cause Yuppie Flu? If only it were true. Then, we could tell everyone with non-specific symptoms that they were suffering from chronic Epstein-Barr virus infection. They'd regain their dignity. It wasn't that they couldn't cope with the hectic pace. No, sir, it was a nasty virus (Saiden, 1987).

Seiden's fictional medical case serves to argue that the woman's refusal to take personal responsibility for her fatigue is merely an attempt to preserve her dignity in the face of those who 'know better.' When media narratives like Seiden's gain traction, they can shape societal interventions and influence risk governance practices (Hunt, 2018, p. 179). The moralization of fatigued working mothers who are eventually diagnosed with CFS can fuel social scrutiny and self-doubt, prompting questions about whether a mother's participation in the paid workforce is so potentially harmful to the family unit that it is not worth the risk. The framing of 'yuppie flu' reinforces this notion, suggesting that the condition results from excessive ambition or greed and that a woman's professional success comes at the expense of family stability. These narratives not only shape how individuals navigate their roles within the family, workplace, and society but also reinforce broader societal expectations of motherhood. Whether someone is perceived as too lazy or too ambitious, unexplained fatigue is often framed as a failure of personal responsibility or moral character, with those affected frequently regarded as burdens on society.

Because a definitive organic cause for CFS remained elusive, researchers in the 1990s revisited psychogenic explanations for the disorder (Franssen, 2020, p. 408). In *The* 

Psychopathology of Functional Somatic Syndromes (2004), Peter Manu and eleven colleagues compiled findings from their research at the University of Connecticut Health Centre between 1986 and 1993. They examined patients with functional illnesses—conditions characterized by persistent, distressing physical symptoms without measurable physiological changes. Their findings suggested that such illnesses were often linked to psychological factors such as neuroticism, excessive health-related anxiety, and maladaptive coping strategies (Manu, 2004, p. 4, 197). Neuroticism was identified as a common trait in many individuals before the onset of CFS and was thought to influence the severity of physical symptoms (Manu, 2004, p. 197). Manu's data also indicated that CFS patients reported a significantly higher incidence of sexual and physical abuse compared to the control group, reinforcing prior research that associated experiences of abuse with neuroticism, poor self-reported health, heightened pain perception, and multiple unexplained physical symptoms (Manu, 2004, p. 211).

However, individuals diagnosed with CFS often resisted acknowledging any psychiatric component to their illness (Manu, 2004, p. 2). In many cases, symptom severity worsened when evaluation and treatment shifted toward psychological therapy after no clear biological cause was identified (Manu, 2004, p. 4). Additionally, skepticism expressed by others regarding the legitimacy of their condition tends to reinforce patients' conviction that an undiscovered physical cause must exist (Larun & Malterud, 2007, p. 24, as cited in Franssen, 2020, p. 410). This resistance to explanations involving personality traits and maladaptive coping strategies may stem from an awareness of stigmas surrounding psychological disorders. Patients may fear being perceived as "weak of character" or undeserving of support (Radley & Billing, 1996, p. 222, 227). Moreover, having their motivations questioned can be particularly distressing as it undermines a patient's sense of self-worth and personal agency (Radley & Billing, 1996, p. 228). Research indicates that the ability to diagnose a disease—its 'diagnosability'—plays a crucial role in how patients perceive and manage their condition (Clarke & James, 2003, p. 1393 as cited in Franssen, 2020, p. 410).

Reports from hospitals and specialty practices treating CFS patients predominantly highlighted the disorder's impact on women (Evengård et al., 1999, p. 457), and until 1999, the U.S. National Institutes of Health (NIH) operated its CFS programs through the Office of Research on Women's Health (Friedman, 2019, p. 3). However, more recent studies indicate that 35-40% of CFS sufferers are men, suggesting the condition does not predominantly affect

women (Friedman, 2019, p. 3). The ongoing portrayal of CFS as a disorder primarily affecting women has reinforced its association with conditions historically tied to female irrationality. This gendered perspective may have led to the misdiagnosis of men by overlooking the possibility that they, too, could be affected and thus denying them representation in medical research on the disorder.

The hypothesis that CFS may result from infection-induced immune deficiency in individuals who have experienced an acute illness (Unger et al., 2016, p. 1437) has long been debated. However, the COVID-19 pandemic has reignited interest in this connection, as many individuals with long COVID exhibit symptoms strikingly similar to those with CFS. Recent research suggests that a significant proportion of long-term COVID patients meet the Centers for Disease Control's (CDC) diagnostic criteria for CFS (Hwang et al., 2023, p. 2). Moreover, a large-scale study of 3,762 long COVID patients across 56 countries found that 56.8% experienced PEM, the hallmark symptom of CFS (Hwang et al., 2023, p. 2). These findings reinforce the theory that CFS is a post-viral condition, suggesting a possible infectious component. This aligns with research from the past decade that increasingly challenges the notion that CFS is primarily a psychological disorder. Instead, while acknowledging that CFS may contribute to reactive depression in some patients, emerging evidence supports a physiological basis for the condition (Unger et al., 2016, p. 1434).

Despite advancements in understanding CFS, managing the condition remains a global challenge, with significant disparities in treatment approaches and availability (Friedman, 2019, p. 2). In many low- and middle-income nations, both the general population and healthcare professionals are unfamiliar with the concept of CFS. In contrast, high-income countries in Northern Europe, North America, and Oceania (Cho et al., 2009, p. 117) frequently endorse cognitive behavioural therapy (CBT) as a means of modifying patient behaviour and thought patterns (Friedman, 2019, p. 2). Some countries fully recognize CFS as an organic disease but struggle with devising effective treatment regimens without a definitive cause (Friedman, 2019, p. 2). Additionally, many global health authorities advocate for the recognition of CFS as a legitimate biological illness and question the appropriateness of continuing to treat CFS as a potential mental disorder (Friedman, 2019, p. 2). While perceptions of CFS vary among health communities worldwide, the International Classification of Diseases (ICD), developed by the World Health Organization (WHO), currently classifies CFS under "Chapter 8: Diseases of the

Nervous System," and it is designated as 8E49 Postviral Fatigue Syndrome (World Health Organization [WHO], n.d.). Proposals to relocate CFS to "Chapter 1: Certain Infectious or Parasitic Diseases" prompted the WHO to conduct a comprehensive literature review (World Health Organization [WHO], n.d.), which ultimately found insufficient evidence to classify CFS as an infectious disease (World Health Organization [WHO], n.d.). As a result, in ICD-11, issued in 2018, CFS remains classified under Diseases of the Nervous System until further evidence justifies reconsideration. (World Health Organization [WHO], n.d.).

The historical and contemporary understanding of CFS has been deeply influenced by societal attitudes, cultural beliefs, and scientific frameworks. From its early associations with neurasthenia and hysteria to its current recognition as a complex and debilitating condition, CFS has been shaped by evolving perceptions of health, morality, and personal accountability. The portrayal of CFS as predominantly affecting women may have led to the misdiagnosis of men, highlighting the need for a more inclusive approach to diagnosis and treatment. Recent developments, such as the recognition of long COVID symptoms resembling those of CFS and the ongoing debate over its classification within the ICD, underscore the importance of continued research. By improving our understanding of CFS, we can develop better treatment strategies and reduce the marginalization of those who suffer from this condition.

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