

# Reflections on the Failure of Legitimate Diagnoses of ME in the 21st Century

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## **Myalgic Encephalomyelitis is a poorly understood Neurological disease**

In the history of several ‘syndromes’ that have been denied the legitimate status of ‘organic disease’. Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) are examples in that it’s status within biomedicine as a ‘real, organic’ diseases is still a matter of controversy. These ‘non- diseases’ or ‘illegitimate illnesses’ are usually defined in terms of symptoms, with few consistent signs, and scientists and doctors have failed to agree on aetiology and pathogenesis. There are no obvious visible abnormalities present in sufferers, and the belief that ME cannot be diagnosed by standard medical tests. The consequences of uncertainty and controversy for those who suffer from ME, is based primarily on Patient Experience who focus on the difficulties in obtaining a correct diagnosis inclusive of miscommunication, dismissal and disbelief. As a result, respondents changed their attitudes towards either particular doctors, or the medical profession. These altered perceptions are discussed in the context of the emergence of critical lay perspectives, and a growing public ambivalence towards biomedicine.

## **Historical Information**

Several descriptions of illness resembling those of chronic fatigue syndrome have been reported for at least two hundred years. In the 19th century, neurologist George Miller Beard popularized the concept of neurasthenia, with symptoms including fatigue, anxiety, headache, impotence, neuralgia and depression. This concept remained popular well into the 20th century, eventually coming to be seen as a behavioral rather than physical condition, with a diagnosis that excluded post viral syndromes. Neurasthenia has largely been abandoned as a medical diagnosis.

In 1938, Alexander Gilliam described an illness that resembled poliomyelitis, interviewing patients and reviewing records of one of several clusters which had occurred in Los Angeles, United States in 1934. The Los Angeles County Hospital outbreak included all or most of its nurses and doctors. Gilliam called the outbreak "atypical poliomyelitis" and described the symptoms as: rapid muscle weakness, vasomotor instability, clonic twitches and cramps, ataxia, severe pain (usually aggravated by exercise), neck and back stiffness, menstrual disturbance and dominant sensory involvement.

Novices and convent candidates at a Wisconsin (USA) convent were diagnosed with "encephalitis" in 1936. Two towns in Switzerland had outbreaks of "abortive poliomyelitis" in 1937, and 73 Swiss soldiers were given the same diagnosis in 1939. Outbreaks in Iceland were called "Akureyri disease" or "simulating poliomyelitis" and were later called "Iceland disease." 800 people in Adelaide, Australia became ill during 1949-1951 with a disease "resembling poliomyelitis." Two smaller clusters in the United States during 1950 were diagnosed as "Epidemic neuromyasthenia" and "resembling Iceland disease simulating acute anterior poliomyelitis." Additional outbreaks of poliomyelitis-like "mystery diseases" occurred from the 1950s through the 1980s, in Denmark, the United States, South Africa, and Australia, among others.

Several outbreaks of a polio-resembling illness occurred in Britain in the 1950s. A 1955 outbreak at the Royal Free Hospital Group was later called Royal Free disease or Benign Myalgic Encephalomyelitis. After the Royal Free Hospital outbreak, a disorder with similar symptoms was found among the general population and the epidemic form came to be considered the exception. Pathology findings, both in monkeys and in rare human casualties, led to the conclusion that the disorder was caused by inflammation of the brain and the spinal cord, particularly the afferent nerve roots, perhaps with neuroimmune etiology.

In the 1960s and 1970s, chronic fatigue symptoms were often attributed to chronic brucellosis, but typically people were seen as having psychiatric disorders, in particular depression. Epidemic cases of Benign Myalgic Encephalomyelitis were called mass hysteria by psychiatrists McEvedy and Beard in 1970, provoking criticism in letters to the editor of the British Medical Journal by outbreak researchers, attending physicians, and physicians who fell ill. The psychiatrists were faulted for not adequately investigating the patients they described, and their conclusions have been refuted. Benign Myalgic Encephalomyelitis was added to the World Health Organization International Statistical Classification of Diseases (WHO ICD) in 1969. A symposium held at the Royal Society of Medicine in 1978 concluded that epidemic Myalgic Encephalomyelitis was a distinct disease entity with a clear organic basis.

The typical illness begins with sufferers starting to experience various inexplicable symptoms, severe enough to warrant giving up work or school. Often, because the symptoms were so mysterious, they were ignored or not 'given in to'

This lack of a credible diagnosis led to problems with employers and family. By not being allowed full, decisive entry into being sick, sufferers found that their social identity devalued and stigmatized. They found it difficult to obtain legitimate absence from work or disability benefit. Interactions with doctors were thereafter conflictual and emotional. Respondents at this point perceived themselves as being at 'rock bottom', where the outlook was bleak and where positive support was absent. The turning point came when respondents discovered ME, often from newspaper or magazine articles, diagnosed themselves, or were diagnosed by a 'pro-ME' professional who accepted the condition and recommended management with possible treatment routes.

The illness gained national attention in the United States when the popular magazine Hippocrates ran a cover story of an epidemic at Lake Tahoe, Nevada, in the mid-1980s. The designation Chronic Epstein-Barr Virus was in use in the U.S., but the magazine used the term "Raggedy Ann Syndrome" to note the fatigue and loss of muscle power patients felt.

History made a detour in the mid 1980's when a similar illness gained national attention in the United States when the popular magazine Hippocrates ran a cover story of an epidemic at Lake Tahoe, Nevada, in the mid-1980s. The designation Chronic Epstein-Barr Virus was in use in medical circles, but the magazine used the term "Raggedy Ann Syndrome" to note the fatigue and loss of muscle power patients felt. It was also coined as "Yuppie Flu" because the area is home to an affluent area called Incline Village at Lake Tahoe, home to career oriented families. Researchers investigating the Lake Tahoe cluster did not find evidence that EBV was involved, and they proposed the name Chronic Fatigue Syndrome (CFS), describing the main symptom of the illness. They published the first working case definition for CFS in 1988. Research increased considerably, and more so after the Fukuda Criteria were relaxed in 1994 .

Patients suffering from unexplained fatigue and what seemed like a prolonged attack of acute mononucleosis were given the diagnosis of chronic mononucleosis or chronic infection with the Epstein-Barr virus. Although the diagnosis has great appeal, the Epstein-Barr virus does not cause the syndrome (CFS) of Chronic Fatigue, which has been renamed and redefined Chronic Fatigue Syndrome to remove the inference that the virus is its cause. From a historical perspective, both syndromes represent the 1980s equivalent of Neurasthenia, a disease of fatigue that influenced the development of psychiatric nosology. Because patients with depression and anxiety also have Chronic Fatigue and because most patients with CFS have an affective disorder, the Psychiatric Collaborative seized their opportunity and introduced their assessment that organic causes of this syndrome requires careful psychiatric diagnosis and treatment. Defining Chronic Fatigue Syndrome as a medical disorder may deprive patients of competent treatment of their affective disorder.

## **The influence of Psychiatrists Changed and continues to change lives forever**

Psychiatric belief argue that CFS/ME is the behavioral and societal response to the disease, where disease is in their terms onto-logically prioritized over the illness. Patients argue that illness can be framed as sufferers' social and cultural response to symptoms. Disease can then be viewed as the doctor's subjective, culturally bound assessment of the 'reality' of their patient's illness, based on a mixture of empirical observations, and theoretical, intersubjective, negotiated and ideological knowledge. Psychiatrists are influential in both their careers and political resources and have built reputations on the belief that only they have the answers. Their assertion that patients can flourish by “sanctions” under the government's 'Expert Patient' initiative, including the use of GET & CBT which exacerbated Patient's symptom and severity levels made it almost impossible to find a compassionate Doctor.

According to the GPs, 'there are rarely any specific issues'. GPs 'can't find anything', possibly because 'there's no disease' to be found. Some also pointed to the lack of scientific knowledge and explanation. For instance, one regretted not having 'an explanation for these conditions in medical science'. Without employing the biomedical frame, GPs thus understood and defined a psycho-social diagnosis, in contrast with “normal” conditions for which evidence is obtainable and medical science has explanations on offer.

The GP explicitly ties his/her doubt to the inability to 'objectively grab a hold' of a reason. It is because he/she 'can't do any blood tests' or the likes that he begins 'to doubt how sick the patient is'. It is noteworthy that lack of evidence results in doubts in patients rather than doubt in medical knowledge. Some voiced suspicion of malingering. For instance, a patient offers a long list of symptoms and a doctor 'couldn't find anything wrong' with them after medical testing and concludes that the patient is unhappy with their job and wanted sick notes for their 'supposed symptoms'. This leaves the patient powerless.

With the growth of the Computer age, Internet and Facebook, today's ME patient is more pro-active about their health and able to diagnose their condition better than their doctors, and often come to the consultation armed with considerable knowledge. This results in doctors' concern that diagnosis is controlled more by the patient than the doctor, the underlying inference being that these patients may not warrant legitimate access to the sick role and thinks that they may be malingering. This behavior is seen to be the cause of difficult doctor-patient relationships by both patients and doctors. Sufferers who are faced with disbelief, dismissal by doctors, other medical professionals feel angry and let down by the system and medical community. Stories of patients suffering at the hands of social workers, psychiatrists and GPs abound in the popular press and in the journals of the sufferers' groups.

Given the background context of political and medical controversy, and the uncertainty of the label, ME experts state that the patient's own understandings and experiences are essential to an analysis of the political and social framework of ME. Internet & Facebook offers a respite to ignorance and opens the door for an understanding of these experiences. Patients world wide reported the same “metaphorical wall” in their interactions with the medical profession. Attempts at obtaining a diagnosis were constantly rejected, symptoms dismissed and disbelieved, and they were often labelled as bored housewives or depressed adolescents. Consequently, acting no longer as passive agents when their needs were not met, respondents actively pursue their own paths to knowledge and challenge the authority and status of their GP's and consultants. What happens next is that doctors question the legitimacy of medicine itself with ME patients than their patients with more easily diagnosed 'legitimate' illnesses. The biomedical frame thus accentuated the lack of objective evidence, the problem of trust and subjective testimony, and various troubling emotions and confusion about the psycho-social narrative made GPs' work difficult. Because the symptoms are 'difficult to assess', sick listing becomes difficult ('what are we to do about it?'), elevating the risk of going into what one GP called 'a stalemate', i.e. an unfruitful therapeutic situation.

**“When the full history of M.E. is written one day  
we will all be ashamed of ourselves”**

As an active Advocate and Patient Stakeholder for 11 years, I hear similar stories from thousands of patients. One has to acknowledge that there are a thousand more because we can't all be imagining it while experiencing "the same yet not quite the same." Each of us has our own personal envelope of symptoms and severity, most likely the body's response to the virus and the trigger

**Patient #1 ME for 8 yrs.**

Like most people I refused to give in at first. I didn't realize there was anything wrong. In the beginning, when the first symptoms started arriving, I had an ear infection, a sore throat, body pain but I didn't stop working. I think, gradually when I looked back I can see everything falling into place. I started to say things back to front, dropped unfinished sentences, couldn't count with money, I was getting very tired when I woke up in the morning, it was as if I hadn't been to sleep, and it got to the point when I collapsed before I went to the doctor.

**Patient #2 with ME for 12 yrs.**

Some Patients attempt to place their illnesses and its onset within the circumstances and emotions of their personal lives, so that causes of their illness is attributed to personal stress and traumatic events. One woman who had a child with Cystic Fibrosis aged 15, associated her illness with the stress caused by looking after her daughter. She had connected the stress of the birth of her daughter to contracting viral meningitis which developed into what was later diagnosed as ME, even though the latter event was many years after the first.

**Patient #3 with ME 7 yrs.**

This man's story revolved around his dismissal from his job, which he believed was grossly unfair: I was stressed at work which resulted in me losing my job then the whole thing just became bigger. My health decline was noticeable, and the day after I went for my appeal against dismissal, I physically collapsed. I think it was the stress that triggered it. He didn't connect it to a viral illness 6 months prior.

Diagnosis of an illness is vital to the psychological and emotional well being of the patient by medical professionals. Doctors report that patients were relieved after a diagnosis of ME/CFS -despite the ambiguity and stigma of this label - as the diagnosis provided a rational, structured meaning system for their experiences of disability and illness. Patients report that they visited several doctors in an effort to find a diagnosis. However, this act of visiting several doctors was perceived as a key to mental illness without consideration of the symptoms. Patients report exacerbating symptoms, from enforced psychiatric Graded Exercise Therapy and Cognitive Behavior Therapy, but no one is listening.

**“One teenager who had spent years trying to obtain a diagnosis finally read about it in a teenage magazine: My Mom & I read this article in a magazine about a young girl who was ill at home and had got ME ... As I read this article I thought this is what I've got and my friends started ringing me up to say it (EB)”.**

This diagnosis, especially when it was a self diagnosis, marked as it usually was by conflict and denial on the part of their own GP, could be seen as a symbolic turning point in patient's change in attitudes towards their doctors. From then on, many expressed the belief that they had improved psychosocially, if not physically, as the illness was given a label and the patient had finally found some respite from the chaos and anarchy of their illness. This appears to be the case despite the uncertainty and stigma surrounding the label ME. At this point in the label ME became both a symbol of the sufferer's own newly acquired empowerment, and of the threat to the doctor's position of authority.

**“Well my doctor was calling it Post Viral Syndrome so I joined FB Support Groups because once it made the news, more people had similar stories. We sort of guessed what it was but at no point did we get diagnosed with the magic words ME. We were certainly not diagnosed by any doctor, they were in fact very cagey about calling it ME.”**

## **The denial of a Valid Diagnosis**

When symptoms are eventually labelled as Myalgic Encephalomyelitis or Chronic Fatigue Syndrome this is often done in a manner that none-the-less denies the validity of the label . One woman whose daughter was ill, recounted that the paediatrician off-handedly mumbled a diagnosis of ME or glandular fever but said that he did not believe in it and advised the mother not to get in touch with ME Groups. When another woman tentatively suggested their own diagnosis of ME, she was told: 'ME does not exist... its all in your head!'. Even when a diagnosis is made, the stigma of the label of ME sometimes results in embarrassment and stress .

Patients with only the rare exception, report that many people, and particularly doctors, misunderstand the nature of their illness. They complained to their doctors of multiple, vague symptoms, often with little physical sign of an organic disease. Various tests prove negative, and, according to both sufferers and doctors, they did not always look sick. These individuals expressed the belief that they experience that they know something is wrong, and expected their doctors to take this knowledge and transfer it into their own understanding.

However, doctors and patients did not share the same language of simple descriptive terms. When patients talked of 'fatigue', they mean a profound depth of fatigue, the inability of movement. To patients, fatigue means being so tired they cannot brush their hair or even sit up in bed. To doctors 'fatigue' may simply mean a term to describe a common occurrence as a result of modern-day stress. Patient's severe symptoms of pain, depression and fatigue were trivialized by doctors, who saw them as common experiences unworthy of a doctor's attention. This breakdown of a shared meaning system, led to confusion and uncertainty of the Doctor-Patient trust.

The common gap between medical and lay approaches in which neither party can find a common language was widened with respect to ME, where patients' experience and doctors' understanding appeared to be so markedly incommensurate. Even though relationships with their doctors deteriorated, patients insisted and continued looking for a legitimate diagnostic goal while remaining in the public medical system to achieve them. Attempts to attain legitimacy took on a moral face as patients global wide became patient advocates to raise awareness for better health care.

As patients started to take a more active role in the diagnostic process sometimes diagnosing themselves, and pushing for other consultants or doctors who could give a more definitive diagnosis, they faced their doctor's perception as a threat to their professional knowledge and power. They, in an attempt to retain control not only over the patient but also over their claim to knowledge, often becoming angry and abusive. Thus highlights the dilemma of diagnostic validity expressed by both doctors and patients. Patients experience serious difficulties in their interactions with doctors finding themselves misunderstood and disbelieved. This 'psychogenic dismissal' response dismissed patients and labelled them as suffering from psychological injury when their symptoms are dismissed. The patient experience becomes disrupted by a serious unknown illness which gives the doctor a powerful point of entry into the patient's psyche, and amounts to a destruction of the patient's conventional understanding.

“Psychogenic Dismissal” unlocks a double disruption of this reality. Patients find it difficult to obtain a satisfactory diagnosis, and because of a lack of diagnosis, they cannot get health care. Acceptance from medical professionals legitimizes an illness. Naming an illness with an authenticated biomedical disease label is entry into health care. When patients aren't allowed to be legitimately sick, they are denied free from responsibility and blame for their illness. Also, their quality of life is eroded to some extent & they are stigmatized. Their social identity devalued, their friends no longer visit, their family doesn't understand while they continue to struggle to obtain legitimate absence from work or disability benefit.

It is a major step to move from challenging individual doctors to an actual rejection of the institution of medicine. The existence of the ME self-help groups challenge modern medicine by privileging lay experience and knowledge, thus providing an opportunity to resist the domination of the life world by the expert system of medicine. The hostility shown towards the ME self-help groups by some doctors and psychiatrists leads one to surmise that these groups do represent a perceived threat.

## Fighting the Stigma

Labelling ME as chronic fatigue syndrome gives doctors, the media, the public, and even family members permission to assume individuals are exaggerating, that we're simply refusing to pull it together. With such a name, who could fault folks for thinking we just need to take a nap, some fish oil, and a vigorous walk? This type of thinking has led to individuals with ME, some too sick to care for themselves, being abandoned by both disbelieving families and physicians.

In October 2015, things seemed poised to break the logjam of government neglect and stigmatizing research. An investigative journalist and public health expert David Tuller successfully debunked the PACE study, a randomized trial that had cemented the widely held but erroneous belief that ME is a psychological disorder rather than a physical illness. Tuller's work showed that the many flaws in the trial's methodology seriously undermined the credibility of the treatments it supported — cognitive behavior therapy and graded exercise therapy. The investigation prompted 42 scientists and experts from Columbia, Harvard, Stanford, Berkeley, and elsewhere to release an open letter to the Lancet supporting Tuller's analysis and demanding an independent analysis of the trial. A tribunal hearing was held and the research from the PACE Trial Study was publicly release via Freedom of Information Act. Also important to note is that there was no proof presented that patients had issued any death threats to the Psychiatric Collaborative, yet death threats have been a constant complaint by those involved in the PACE Trials.

**Myalgic Encephalomyelitis is categorized by the World Health Organization ICD 10 as a neurological condition but CFS was not. The WHO ICD 11 have added CFS under the tab of Post Viral but it should be noted it is not added as ME/CFS or CFS/ME—they are both listed distinctly as ME and as CFS.**

There are numerous Criteria floating around the world used by medical professionals to diagnose ME patients but the majority of them describe patients with a milder form of ME or CFS. Researchers believe that CFS is a milder form of ME but not one CFS criteria includes encephalomyelitis and the American CDC who coined the Lake Tahoe/Incline Village ME breakout as “Chronic Fatigue Syndrome do not acknowledge that ME exists. Canadian Dr B Carruthers led a team of experts to present the International Consensus Criteria in 2011. The ICC dismisses CFS as a diagnoses for Myalgic Encephalomyelitis which is Latin for Muscle Pain & Inflammation of the Brain & Spine.

“The label ‘Chronic Fatigue Syndrome’ (CFS) has persisted for many years because of the lack of knowledge of the aetiological agents and the disease process. In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term ‘Myalgic Encephalomyelitis’ (ME) because it indicates an underlying pathophysiology. It is also consistent with the neurological classification of ME in the World Health Organization’s International Classification of Diseases (ICD G93.3). Consequently, an International Consensus Panel consisting of clinicians, researchers, teaching faculty and an independent patient advocate was formed with the purpose of developing criteria based on current knowledge. Thirteen countries and a wide range of specialties were represented. Collectively, members have approximately 400 years of both clinical and teaching experience, authored hundreds of peer reviewed publications, diagnosed or treated approximately 50,000 patients with ME, and several members coauthored previous criteria. The expertise and experience of the panel members as well as PubMed and other medical sources were utilized in a progression of suggestions/drafts/reviews/revisions. The authors, free of any sponsoring organization, achieved 100% consensus through a Delphi type process. The scope of this paper is limited to criteria of ME and their application. Accordingly, the criteria reflect the complex symptomatology. Operational notes enhance clarity and specificity by providing guidance in the expression and interpretation of symptoms. Clinical and research application guidelines promote optimal recognition of ME by primary physicians and other healthcare providers, improve the consistency of diagnoses in adult and paediatric patients internationally and facilitate clearer identification of patients for research studies.”

<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2796.2011.02428.x>