

Chronic Fatigue Syndrome is Back!

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But the new Institute of Medicine report is driven by politics, not science

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Just when you thought a stake had been driven through the heart of [Chronic Fatigue Syndrome \(CFS\)](#) it comes roaring back, propelled this time by a committee of the Institute of Medicine (part of the National Academy of Sciences). It's a committee that the CFS patients' lobby has roped, captured, and hogtied. How the Institute of Medicine could have let itself in for this [embarrassment](#) is a mystery. Their report is valueless, junk science at its worst.

CFS came out of that whole brew of toxic beliefs about being tired all the time that arose in the 1970s; it became crystallized with the diagnosis "Chronic Epstein-Barr Virus Infection," then morphed into Chronic Fatigue Syndrome (Myalgic Encephalomyelitis, or "ME," in the UK). Finally, the wind went out of this particular sail late in the 1990s when it became apparent to the patients that nobody believed they had a distinct organic disease, as real as mumps, called "CFS."

I described this sometime ago in my book, *From Paralysis to Fatigue: Psychosomatic Illness in the Modern Era* (Free Press, 1992). Nothing has changed since then in scientific terms. There have been no convincing new studies, no breakthrough findings of organicity, nothing.

And there never will be.

But this new Institute of Medicine report is driven by [politics](#), not science. And politics means bringing patients groups on board. But bringing militant advocates into such a discussion is equivalent to a committee of geographers that includes members of the Flat Earth Society.

What drives this process? Patients hate having a diagnosis that nobody believes in; they dread the words, "Madame, it's all in your head." So, many CFS sufferers moved on to other delusional illness attributions, some involving the [environment](#) rather than the mysterious collapse of their "immune systems."

But not all moved on. CFS has proved to be a remarkably stubborn lobby, and, led by the women's office of Human and [Health](#) Services, the lobby managed to [persuade](#) the Institute of Medicine to undertake a study, the outcome of which was a foregone conclusion: The committee wants "the positioning of ME/CFS as a legitimate disease." (10)

But since the 1970s the CFS lobby has been clamoring for recognition as a disease. The remarkable thing is that they were able to capture this committee, and capture they did: the report abounds with acknowledgments of thanks to the patients and their advocates. The publications of the Chronic Fatigue and Immune Dysfunction Syndrome Association of America are given prominent mention, while the writings of the many critics, such as the internist Nortin Hadler at the University of North Carolina, are not cited at all.

CFS lobbyists actually sat on the committee, and in the several public hearings the CFSers appeared in mass to pour out their tales of woe. In its report the committee emphasized that it is "taking into account the clearly expressed views of hundreds of patients and their advocates." (xv)

Now, committee capture works like this: It is impossible to say to some woebegone victim – who has now become a committee colleague – "We don't believe that your symptoms are caused by an organic disease." The public hearings were a circus, with moaning and groaning victims right and left. How do

you say to this kind of psychodrama: “We are scientists and insist on evidence other than the tireless repetition of your subjective complaints.”

You don’t. That’s not the way a “consensus committee” works. You piece off everybody at the table.

And the committee pieced off the CFSers big time. They came up with a new name. Wait for it. “The Systemic Exertion Intolerance Disease.” How do we diagnose the SEID? “Exertion of any sort – physical, [cognitive](#), emotional – can adversely affect these patients in many organ systems.” (11)

OMG. Exertion of any sort. Emotional exertion can tip you over the edge. Physical exertion, very bad. In fact, one of the principal symptoms is fatigue while standing up. Best is [lying](#) down. A big theme of the movement over the years has been hostility to exercise, which becomes a kind of Clockwork Orange nightmare for a society such as ours that believes in fitness and activity.

Another bugbear for the movement is [psychiatry](#), and nothing about psychiatry appears in the report, filled as it is with unreproduced microfindings about this protein or that hormone. But, rather than SEID, what many of these patients have is a kind of delusional somatization, the unshakeable belief that something is wrong with their bodies rather than their minds.

The tragic element is that becoming involved with a CFS advocacy group is a recipe for lifelong disability, further entombing the patients in their symptoms. Yet it is precisely the advocacy groups that are driving the whole carnival, that have captured this wacky committee of the otherwise august Institute of Medicine. This is the politics of health care at its worst: giving over to noisy advocates the responsibility for defining disease entities. It encourages patients to believe that they have a non-existent illness, and it intimidates physicians from making the correct diagnosis and ensuring that these patients receive proper care rather than Rose of Sharon Oil.