

PE1690/N

Michael VanElzakker submission of 16 August 2018

I am a researcher at Harvard Medical School and Massachusetts General Hospital, studying the medical condition myalgic encephalomyelitis (ME), sometimes known as chronic fatigue syndrome (ME/CFS).

In 2015, the United States' Institute of Medicine/ National Academy of Medicine (IOM/NAM) conducted an extensive review of this condition, finding that "ME/CFS is a serious, chronic, complex systemic disease that often can profoundly affect the lives of patients." I believe this review should be examined by anyone who is interested in understanding this condition from a clinical, scientific, social, or political standpoint:

<http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>

In summarizing the IOM/NAM report, Ganiats (2015) wrote in the Annals of Internal Medicine, "The literature review found sufficient evidence that ME/CFS is a disease with a physiologic basis. It is not, as many clinicians believe, a psychological problem that should not be taken seriously."

<http://annals.org/aim/article-abstract/2118972>

The cardinal symptom of this condition is known as "post-exertional malaise" (PEM), which is a worsening of symptoms after exertion. Due to the combination of an imprecise name and social stigma against invisible illnesses (i.e., illnesses that do not have an obvious outward identifier - one cannot "see" ME/CFS like one can see a bruise), many believe that this condition is simply a matter of "feeling tired" but in fact, it is more like a long-term flu that will not relent. Essentially, it can feel like a flu that lasts for years. This includes profound fatigue but in some cases also includes a sore throat, muscles aches, difficulty concentrating, and unrefreshing sleep, and even sensitivity to light and sound, migraines, and autonomic problems. This condition is not triggered by deconditioning: they are not sick because they are in bed, they are in bed because they are sick. Long-term bed-rest immobility is not good for anyone, but it is not the case that these factors are the primary reason patients remain ill. It follows that forcing exercise will not get them better.

Serious biomedical research into this condition is ongoing, and points to problems with mitochondrial function, possibly due to a neuroinflammatory trigger. There are several reasonable working theories. It is important to keep in mind that the basic mechanisms of how the immune and nervous systems communicate are still being worked out in basic research - in other words we do not yet understand how everything in the body works, and this is an important part of why we still do not understand how many diseases work. Support from Scotland's creative and thoughtful scientific community would be most welcome, both in clinical research ("How should we treat these patients?") and more basic science ("How do the basic mechanisms of immunology and metabolism work?"). A reliably-supported Scottish Center For Excellence specifically focused on this kind of research would be a significant help to the worldwide effort to understand and effectively treat

ME/CFS.

Like all sick people in a compassionate society, people with ME/CFS deserve support. They also deserve thoughtful care, and this does not mean subjecting them to therapies that will make them worse. By definition, these patients' symptoms are triggered by exertion, and doctors should not force graded exercise therapy (GET). Most patients are expert in understanding what their own limits are, and most patients do precisely the amount of activity they are able to do without triggering PEM. Patients can benefit from supportive psychotherapy in the same way that all of us can, but psychotherapy ceases to be supportive if its central message is "You are not really sick." The combination of forced exercise and "therapy" that includes telling patients, "You are not really as sick as you think you are" is sometimes known as GET/CBT and the studies that recommend this clinical approach are far too flawed to justify their outsized influence on clinical practice. I literally teach some of these papers in research methods classes and have found that undergraduate university students are able to discern why the conclusions of such studies are, at best, shaky. More specifics are laid out here:

<http://www.virology.ws/2016/02/10/open-letter-lancet-again>

<http://journals.sagepub.com/toc/hpqa/22/9>

Importantly: in practice, the diagnosis of ME/CFS still functions somewhat as a "diagnosis of exclusion." This means that, often, a diagnosis means that an individual doctor was unable to discern what may be causing a patient's symptoms. Given the fact that this condition is almost never taught in medical school, it often means that a doctor is unaware of the common neurological, immune, metabolic, and autonomic symptoms but is instead making a diagnosis based upon the imprecise name of "chronic fatigue syndrome." There are many reports of patients who had been diagnosed with "ME" or "CFS" only to later learn that their fatigue-related symptoms are actually being driven by a neurological abnormality (e.g., Chiari malformation) or allergy, or viral infection, or lead poisoning, or some other issue. That is to say: medical skepticism about this diagnosis should be not be turned outward ("Perhaps this patient's behavior and beliefs are why they aren't getting better") but rather turned inward ("Perhaps we doctors missed something, or perhaps we scientists don't yet understand the mechanisms of health and illness well enough").

Please feel free to reach out if I can be of any help.