



Solve ME/CFS Initiative

Leading the Fight to cure ME/CFS

December 18, 2020

Dear Mr. Grinker,

When I read the closing paragraphs of “When the Body Speaks,” I had to pause and double check the date it was published. I was shocked and disappointed to find such outdated views about ME/CFS in an article dated December 16, 2020.

My name is Emily Taylor and I’m the Advocacy and Community Relations Director for the Solve ME/CFS Initiative (Solve M.E.). We are a non-profit research and advocacy organization dedicated to accelerating the discovery of safe and effective treatments for Myalgic Encephalomyelitis, formerly known as Chronic Fatigue Syndrome, or ME/CFS.

In addition to research and advocacy, an important part of our work involves debunking fallacies and misinformation about this devastating disease, which cause active harm to people with ME/CFS. For example, Multiple Sclerosis (MS) was once also falsely characterized as a form of psychosomatic deconditioning. But, after the invention of the MRI machine, which provided images of lesions on the brain and spinal cord, the medical community moved away from this incorrect and archaic depiction of MS. ME/CFS is subject to a similar mischaracterization and this includes the assertions expressed in your article and others like it.

In your *Psychology Today* article, you wrote:

“Clinical research has shown that the most effective treatment for many chronic multi-symptom conditions, like chronic fatigue syndrome/myalgic encephalomyelitis, is a combination of exercise, cognitive behavioral therapy (CBT), and psychotherapy, findings that infuriate many people with CFS/ME.[v] Exercise is crucial because a lack of exercise exacerbates fatigue through deconditioning, and it can lead to a wide range of other medical problems.”

I am writing to bring your attention to the inaccuracies presented here and ask you to correct them in order to avoid further harm to millions of people with ME/CFS.

First, a review of clinical research does not show that exercise, CBT and psychotherapy are effective treatments for ME/CFS. A review of the published literature shows mixed results, while a review of reports from patients clearly show exercise and Graded Exercise Therapy (GET) cause harm. In a 2019 patient survey, **81.1% of respondents with ME/CFS reported that their symptoms worsened as a result of GET treatment**ⁱ. In fact, *just last month* the treatments you suggest were removed from the National Institute for Health and Care Excellent (NICE) guidelines making national headlines in the United Kingdom. Please take a moment review the recent articles which clearly articulate the harm caused by these treatment recommendations:



- The Telegraph: [Stop telling people with ME to increase their exercise, new guidance says](#) | 10 November 2020
- The Guardian: [ME/Chronic fatigue syndrome Fatigue syndrome exercise therapy loses Nice recommendation](#) | 10 November 2020
- Medscape: [Treatment Guidance for ME Proposes Curbs on Graded Exercise Therapy](#) | 10 November 2020
- British Medical Journal: [NICE backtracks on graded exercise therapy and CBT in draft revision to CFS guidance](#) | 10 November 2020
- Pharmaceutical Journal: [NICE reverses advice on exercise therapy for treatment of chronic fatigue syndrome in draft guidance](#) | 11 November 2020

The NICE guideline amendment follows a similar decision by Centers for Disease Control (CDC) when they [also removed GET](#) from their website and treatment recommendations **in 2017**. I highlight these agency actions because these prominent leading entities have already abandoned the harmful assertions from your article, which you continue to espouse.

Additionally, you cite a 2003 Gulf War Illness study as evidence for your comments. This is an outdated study that did not evaluate people with ME/CFS. Allow me to direct your attention the more recent, relevant publications, which draw very different conclusions:

- Twisk FN, Maes M. [A review on cognitive behavioral therapy \(CBT\) and graded exercise therapy \(GET\) in myalgic encephalomyelitis \(ME\) / chronic fatigue syndrome \(CFS\): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS](#). *Neuro Endocrinol Lett.* 2009;30(3):284-99. PMID: 19855350. Accessed 18 December 2020.
- Vink M, Vink-Niese A. [Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe](#). Re-analysis of a Cochrane review. *Health Psychol Open.* 2018;5(2):2055102918805187. Published 2018 Oct 8. Accessed 18 December 2020.
- Moss-Morris R, Sharon C, Tobin R, Baldi JC. [A Randomized Controlled Graded Exercise Trial for Chronic Fatigue Syndrome: Outcomes and Mechanisms of Change](#). *Journal of Health Psychology.* 2005;10(2):245-259. Accessed 18 December 2020.
- Carolyn Wilshire, Tom Kindlon, Alem Matthees & Simon McGrath (2017) [Can patients with chronic fatigue syndrome really recover after graded exercise or cognitive behavioural therapy? A critical commentary and preliminary re-analysis of the PACE trial](#), *Fatigue: Biomedicine, Health & Behavior*, 5:1, 43-56, Accessed 18 December 2020.
- Vink M, Vink-Niese A. [Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe. Re-analysis of a Cochrane review](#). *Health Psychol Open.* 2018;5(2):2055102918805187. Published 2018 Oct 8. Accessed 18 December 2020.
- Larun L, Brurberg KG, Odgaard-Jensen J, Price JR. [Exercise therapy for chronic fatigue syndrome](#). *Cochrane Database of Systematic Reviews* 2019, Issue 10. Art. No.: CD003200. Accessed 18 December 2020.

Secondly, to your point regarding deconditioning. ME/CFS is not a “psychosomatic” illness and the symptom we call [Post Exertional Malaise \(PEM\)](#) is not “deconditioning.” Decades of rigorous scientific research in tens of thousands of publications have yielded substantial scientific evidence outlining the various biological abnormalities inherent in people with ME/CFS. Most notably, I suggest you review the many study results of [two-day cardiopulmonary exercise tests](#) on people with ME/CFS and invite you to explain these results using your “deconditioning” assumptions. Furthermore, the literature tells us that ME/CFS is often triggered by an acute infection, such as COVID-19.



Promotion of the incorrect notion that ME/CFS is a “psychosomatic” illness, despite vast quantities of scientific research proving otherwise, causes unnecessary pain and suffering to patients and their families, promotes mistreatment of people with this disease, and contributes to the failure of the medical community to provide proper care to people suffering from significant biological impairments. It also contributes to the continuing misdiagnosis of gravely ill people. According to the 2015 Institute of Medicine report, between 84-91% of people with ME/CFS are undiagnosed or misdiagnosed.

The human cost of incorrectly labeling ME/CFS as a “psychosomatic disorder,” is very real. Even further harm is caused by incorrectly characterizing the disease’s hallmark symptom, Post Exertional Malaise (PEM), as “deconditioning.” Your story has actively contributed to misinformation harming people with ME/CFS today.

The only correct and responsible course of action is retracting the incorrect statements in your article, correcting your false characterization of ME/CFS, and issuing an immediate apology to the international ME/CFS community.

Sincerely,

A handwritten signature in black ink that reads "Emily Taylor". The signature is fluid and cursive, with a long horizontal stroke at the end.

Emily Taylor
Director of Advocacy and Community Relations
Solve ME/CFS Initiative

P.S. As the daughter of a person with ME/CFS, I have seen first-hand the damage misinformed comments like yours can cause. If you still feel otherwise, I invite you to join me for a day in my virtual workspace to meet people who have lived these experiences and hear their stories. Their physical, financial and emotional harm is very real. I urge you to be part of the solution, rather than part of the problem.

ⁱ <https://meassociation.org.uk/wp-content/uploads/NICE-Patient-Survey-Outcomes-CBT-and-GET-Final-Consolidated-Report-03.04.19.pdf>