

PERSONAL NARRATIVE

The Importance of Listening in Treating Invisible Illness and Long-Haul COVID-19

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Abstract

Primary and specialty care clinicians strive to base diagnoses and treatment on specific, measurable abnormalities. Yet those with invisible, controversial illnesses such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) often have symptoms not explained by standard laboratory values. For instance, one of the cardinal features of ME/CFS is postexertional malaise, the exacerbation of symptoms—fatigue, pain, cognitive dysfunction—following exertion, which contradicts studies showing the health benefits of exercise. In these cases, overly physicalist approaches to caring for patients are not likely to be helpful, and a clinician’s willingness to listen to a patient’s experience of illness becomes essential.

Onset

In 1978, when I was 30, I became ill with a vicious case of mononucleosis from which I never fully recovered. Since then, I’ve become accustomed to conducting my work, home, and social life at about half my pre-illness energy level, and I am unable to exercise normally. I remember clearly those early years of illness, lying in a state of exhaustion on my couch, not understanding why I felt a heavy pressure like a weight pushing my body down. Maybe I need fresh air, some exercise, I thought. I’d pull myself up and put one foot in front of the other up the street. Within 20 yards I’d feel heavy as lead, my head swimming in a thick swamp of exhaustion. My body was telling me loud and clear: I needed rest, not exertion.

Aftermath

Although I knew instinctively that I was experiencing the chronic aftermath of mono—constant sore throat, swollen glands, brain fog, fatigue—all lab values were normal. I have an enduring memory of physicians peering at me with suspicion when I described my symptoms: Was I experiencing family problems? Work stress? Depression?

It wasn’t until 1988 that the Centers for Disease Control and Prevention (CDC) recognized this illness and gave it the radically misleading name, *chronic fatigue syndrome* (CFS), as if those of us with CFS were just tired from busy lives.¹ Today, this illness is called *myalgic encephalomyelitis/chronic fatigue syndrome* (ME/CFS) and is

more widely understood as a serious illness, but clinical suspicion and misunderstanding persist.² The majority of textbooks and health professions curricula still include little or nothing about ME/CFS,³ and even well-intentioned clinicians often cannot provide the information their patients need.

A neurologist I saw recently, trying to help me stay active, raised her eyes from her computer screen to encourage me. “I read a study recently that recommended graded exercise for CFS.”

I was seated on the crinkly paper of the exam table, not sure where to begin. This assertion gets me—and so many patients with ME/CFS—where it hurts, since I love to exercise and for decades have tried repeatedly, and failed repeatedly, to increase how far I can walk. I took a breath. “Studies recommending graded exercise for ME/CFS have been discredited,” I said. “Or they included people who were depressed, who do benefit from exercise. But for people with ME/CFS, if we push ourselves to do more, we can make ourselves worse. That’s been my experience.”

She shrugged, “I can’t remember where I read it, but the study did recommend graded exercise.”

My time was up, and I left it at that. But this brief medical encounter was a complex moment, frustrating for me and probably for her, too. It’s worth unpacking.

My neurologist’s recommendation was based on an article she’d read—which she assumed to be based on reliable science—that concluded graded exercise therapy (GET) could produce positive outcomes for those with ME/CFS. Yet I knew from 42 years of experience that my pain and fatigue get worse if I consistently increase my exercise despite how I’m feeling, as GET recommends. I’m like a car with one piston. I can go 10 miles an hour. But if I try to go 20 miles per hour next week, 30 the next, 40 the next, the car will simply break down. To go faster, I have to fix the car (something no one yet knows how to do).

My exchange with the neurologist didn’t simply reflect conflict between **biomedical and experiential** ways of knowing or a dispute over who owns expertise. In fact, there are many reasons why my physician and I are in the positions we’re in—reasons having nothing to do with evidence-based science.

Making ME/CFS Invisible

First, the National Institutes of Health (NIH) has consistently failed to fund robust investigations of ME/CFS, although between 836 000 and 2.5 million adults in the United States are estimated to have ME/CFS, with annual health care costs and lost productivity estimated to be between \$17 and \$24 billion.³ While there have been “thousands of studies” over the past 35 years revealing alterations in the immune, autonomic, and neuroendocrine systems in those with ME/CFS compared to controls,² most of these studies were small and often privately funded, and many clinicians remain unaware of this information.

Yet many researchers find the evidence of these alterations compelling. ME/CFS researcher and clinician Nancy Klimas, professor of medicine at Nova Southeastern University, cites the “strong evidence of neuroinflammation, systemic inflammation, autonomic dysfunction, and oxidative stress” in studies by many investigators.⁴ Exercise

physiologist Staci Stevens and her team in Ripon, California, use a 2-day cardiopulmonary exercise test, which shows a significant drop in energy production (oxygen consumption) on the second day of exercise for ME/CFS patients compared to controls, as well as lower heart rate, blood pressure, and arterial oxygen saturation.⁵ Particularly in light of these and other studies' compelling findings, the absence of national, large-scale NIH research support is keenly felt and is another way the voices of those with ME/CFS have been marginalized and ignored.

Second, the case definitions used to guide research and clinical care for patients with ME/CFS since 1988 have de-emphasized postexertional malaise (PEM), despite the fact that PEM is a hallmark of the illness.^{1,3,6} Not until 2015 did the Institute of Medicine (IOM, now the National Academy of Science) create a new clinical case definition of ME/CFS that recognizes PEM as a central symptom, defining it as “worsening of a patient’s symptoms and function after exposure to physical or cognitive stressors that were normally tolerated before disease onset.”³ As Leonard Jason, professor of psychology at DePaul University, has pointed out, without a rigorous, effective case definition, further research, search for biomarkers—which many see as an empirically verifiable indicator of legitimacy for a disease or its symptoms—and treatment are all on tenuous ground.⁷

Most upsetting to patients has been the **ongoing mischaracterization** of ME/CFS as psychiatric in origin, which found its strongest voice in the PACE trial, published in *The Lancet* in 2011.⁸ Led by a group of British psychiatrists and mental health professionals who had long proposed that patients with ME/CFS were making their illness worse through unhelpful illness beliefs and deconditioning, it was no surprise that the study claimed cognitive behavioral therapy (CBT) and GET to be effective treatments for ME/CFS.^{8,9}

The Lancet posted the study as an open-access article, the authors gave many interviews, and the press pounced. As of April 2019, the study had been cited 675 times by other journals,¹⁰ and the media carried headlines, such as “Psychotherapy Eases Chronic Fatigue Syndrome, Study Finds” (*New York Times*), “Pushing Limits Can Help Chronic Fatigue Patients” (*Reuters*), and “Therapy, Exercise Help Chronic Fatigue Syndrome” (*WebMD*).¹⁰

The PACE study has since been roundly critiqued by patients, academics, and experts alike for serious methodological flaws.⁹ A subsequent 2018 reanalysis of the PACE results published in the peer-reviewed journal *BMC Psychology* “documented that the benefits for CBT and GET reported in multiple PACE papers were either exaggerated or illusory when the data were assessed per the methods detailed in the trial’s published protocol.”¹¹ The CDC has since retracted its support for GET and CBT as treatments for ME/CFS, as has the National Institute for Health and Care Excellence, which provides treatment guidelines for the UK health system.^{11,12} But headlines stick in the minds of the public, media, and medical practitioners long after they’re debunked.

Research investigating exercise in ME/CFS by Leonard Jason and colleagues at DePaul University, which received much less media attention, reveals “potential difficulties using graded activity approaches.”¹³ Contrary to the PACE findings, Jason and colleagues recommend that patients follow the energy envelope theory, in which patients monitor their perceived energy capacity and stay within those boundaries on any given day. The authors state: “We learned that by avoiding overexertion, people with

CFS could avoid setbacks and relapses while also increasing their tolerance for activity”¹³—something ME/CFS patients have long understood.

Listening to Patients

I knew, as I left my neurologist’s office that day, that she couldn’t be expected to keep up on the latest information about ME/CFS. It’s not uncommon for informed patients with ME/CFS to know more about their illness and the current research than their physicians. But I do expect the following:

1. Physicians unfamiliar with the latest clinical science about ME/CFS will listen to me and respect me as a reliable narrator of my illness experience, *and*
2. When my narratives of my experience conflict with physicalist clinical views that privilege measurability, physicians will acknowledge the limitations of their diagnostic technologies, the contingent nature of biomedical “knowing,” and how social factors shape disease perception.

Had government institutions, researchers, and clinicians taken patients’ subjective reports of illness seriously over the last 35 years, I and others with ME/CFS could today enter a medical office and find physicians who could more effectively guide our care. Until that happens, physicians must have, as Nancy Klimas pointedly says, “the ability to say ‘I don’t know’ rather than ‘there is nothing wrong with you.’ Some **medical humility** is a critical part of being a good doctor.”⁴

Stay Tuned

In a devastating twist no one anticipated, we’re now seeing significant numbers of Covid-19 patients who continue to have debilitating symptoms, including PEM, months after contracting the SARS-CoV-2 virus or a variant, the so-called Covid long-haulers.¹⁴ Anthony Fauci, head of the National Institute of Allergy and Infectious Diseases, has said: “And it’s extraordinary how many people [with Covid-19] have a postviral syndrome that’s very strikingly similar to myalgic encephalomyelitis/chronic fatigue syndrome. They just don’t get back to normal energy or normal feeling of good health.”¹⁵ He and many others have been stressing the urgent need for a coordinated effort—among researchers, physicians, government agencies, patients, and policymakers—to collect data on people with ME/CFS and Covid-19 long-haulers. On February 23, 2021, the NIH announced a major new initiative—with \$1.15 billion in funding from Congress over 4 years—to study the long-term effects of SARS-CoV-2 infection.¹⁶ This initiative should increase our understanding of Long Covid and other postviral syndromes and finally make them more visible.

References

1. Holmes GP, Kaplan JE, Gantz NM, et al. Chronic fatigue syndrome: a working case definition. *Ann Intern Med.* 1988;108(3):387-389.
2. Komaroff A. Advances in understanding the pathophysiology of chronic fatigue syndrome. *JAMA.* 2019;322(6):499-500.
3. Institute of Medicine. *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.* National Academies Press; 2015.
4. Flynn C. Dr Nancy Klimas talks ME/CFS and the need for better medical education with SheKnows.com. Solve ME/CFS Initiative. Accessed August 5, 2020. <https://solvecfs.org/dr-nancy-klimas-talks-me-cfs-and-the-need-for-better-medical-education-with-sheknows-com/>
5. Workwell Foundation. Testing for disability. Accessed August 5, 2020.

- <https://workwellfoundation.org/testing-for-disability/#brochure>
6. Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A; International Chronic Fatigue Syndrome Study Group. The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Ann Intern Med*. 1994;121(12):953-959.
 7. Johnson C. Excluding factors: Jason critiques the IOM definition for ME/CFS. *Health Rising* blog. July 19, 2015. Accessed August 5, 2020. <https://www.healthrising.org/blog/2015/07/19/excluding-factors-jason-critiques-the-iom-definition-for-mecfs/>
 8. White PD, Goldsmith KA, Johnson AL, et al. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *Lancet*. 2011;377(9768):823-836.
 9. Tuller D. Trial by error: the troubling case of the PACE chronic fatigue syndrome study. *Virology Blog*. October 21, 2015. Accessed August 5, 2020. <https://www.virology.ws/2015/10/21/trial-by-error-i/>
 10. Johnson C. David Tuller on exposing the bad science behind the biopsychosocial effort to define ME/CFS. *Health Rising* blog. April 17, 2019. Accessed August 5, 2020. <https://www.healthrising.org/blog/2019/04/17/tuller-bad-science-biopsychosocial-chronic-fatigue-me-cfs/>
 11. Tuller D. Trial by error: the 2018 PACE reanalysis and the SMC's expert appraisals. *Virology Blog*. January 13, 2020. Accessed August 5, 2020. <https://www.virology.ws/2020/01/13/trial-by-error-the-2018-pace-reanalysis-and-the-smcs-expert-appraisals/>
 12. Johnson C. Get This! NICE pulls the plug on graded exercise therapy and CBT as treatments for ME/CFS. *Health Rising* blog. November 13, 2020. Accessed January 21, 2021. <https://www.healthrising.org/blog/2020/11/13/nice-discards-graded-exercise-therapy-cbt-treatment-chronic-fatigue-syndrome/>
 13. Jason LA, Brown M, Brown A, et al. Energy conservation/envelope theory interventions. *Fatigue*. 2013;1(1-2):27-42.
 14. Yong E. Long-haulers are redefining COVID-19. *Atlantic*. August 19, 2020. Accessed May 13, 2021. <https://www.theatlantic.com/health/archive/2020/08/long-haulers-covid-19-recognition-support-groups-symptoms/615382/>
 15. Topol EJ, Verghese A, Fauci AS. Fauci to Medscape: "We're all in it together and we're gonna get through it." *Medscape*. July 17, 2020. Accessed August 20, 2020. https://www.medscape.com/viewarticle/933619#vp_2
 16. Collins FS. NIH launches new initiative to study "Long COVID." National Institutes of Health. February 23, 2021. Accessed April 3, 2021. <https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid>

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