

Severe ME Patients' Letter to the IOM

December 16, 2014

To the Institute of Medicine Committee on Diagnostic Criteria for ME/CFS:

We are nine patients from three countries who have severe or very severe myalgic encephalomyelitis (ME). The world doesn't hear from us very often because our extreme disabilities make it difficult for us to communicate. All of us are homebound, bedbound, or largely bedbound and need help with basic activities of daily living (ADLs) such as bathing, dressing, and feeding ourselves.

We live in nursing homes, our childhood bedrooms, and subsidized housing. At least two of us can't walk at all. Some of us have not been able to leave our homes for many years. Most of us can almost never leave our beds. We all score 10 or below on the Bell Disability Scale.¹

We are writing to protest the harmful pro-exercise treatment guidelines for the severely ill written by the Centers for Disease Control (CDC). We strongly disagree with the two patient groups that support these guidelines.

We Oppose CDC Guidelines

The CDC seems to think that we, the severely ill patients, can magically increase our activity level--without any improvement in underlying pathologies--just by trying harder. The CDC website says:

Modifying Exercises for Severely Ill Patients

A subset of people with CFS are so severely ill that they're largely housebound or bedbound. They require special attention, including a modified approach to exercise. Hand stretches and picking up and grasping objects may be all that

can be managed at first. Gradually increasing activity to the point patients can handle essential activities of daily living — getting up, personal hygiene and dressing — is the next step.

A realistic goal with severely ill patients is focusing on improving flexibility and minimizing the impact of deconditioning so they can increase function enough to manage basic activities.²

While this advice might sound reasonable to healthy people and to mildly or moderately ill patients, it has the potential to cause great harm to those of us who are severely ill. Any form of externally imposed graded activity, however mild, can have devastating effects on us, the sickest patients, if the activity is beyond our energy envelope. Such exertion can lead to disease progression. Many of us experienced a dramatic worsening of our health from forced exercise programs, plummeting from mild/moderate ME to severe.

If it were possible to gradually increase our activity to the point where we “can handle essential activities of daily living,” we would have done so already.

While all ME patients should approach graded exercise with extreme caution, such “therapy” can be especially harmful to severe patients. This point was emphasized by Dr. Kenneth J. Friedman, a former professor of pharmacology and physiology at the New Jersey Medical School. He said in an interview with Medscape Medical News: “If you're lying in bed and you can't move your head and you have to speak in whispers, graded exercise therapy is not going to help you, and were you to attempt it, it would most likely kill you.”³

CDC Guidelines Are Unsupported and Unsafe

It is a mystery why the CDC has issued this pro-exercise recommendation for the severest patients. The advice is not based on studies of severe patients. We are usually excluded from research of any kind, especially studies that require patients to travel to a

center, sit upright for hours, fill out paperwork and perhaps even exercise.

Indeed, Dr. Neil C. Abbot, Research and Operations Director for ME Research UK, wrote: "...[S]everely affected people with ME are doubly disadvantaged: not only is this illness under-researched compared with other chronic conditions, but the most severely ill group of patients is under-represented in what little research is done."⁴

It's unclear if the CDC will *ever* study the severest patients. To do so, it would have to send phlebotomists and other medical personnel into our bedrooms because travel is extraordinarily difficult or impossible for us. In a public conference call on September 10, 2013, Dr. Elizabeth Unger of the CDC claimed that for the first time, the CDC would study the sickest patients via home phlebotomy.⁵ However, to our knowledge, the CDC has done nothing to follow up on her promise.

The CDC advice cannot be based on clinical observations, since most doctors are not willing to make house calls and have never personally examined a severe ME patient. The few doctors who *do* make house calls for the severely ill know that forced activity programs can cause decline. And the CDC advice is certainly not based on reality. We--the severe patients--have found that deliberate movement as part of an activity program siphons energy away from necessary ADLs such as brushing our teeth and lifting a fork to our mouths.

Unfortunately, the CDC guidelines, which are not evidence-based, were quoted at length in a "continuing medical education" course for professionals co-sponsored by the CDC and CFIDS Association of America (CAA)⁶ in the mid-2000s. Who knows how many doctors were influenced by this wrong and potentially harmful information, and how many patients suffered as a result?

More recently, the patient group Pandora quoted and apparently endorsed these CDC guidelines for the severely ill under the subhead

“Treatment Recommendations” in a letter to you dated January 22, 2014.⁷ In addition to quoting the CDC verbatim, the letter says, “A way to identify those in different levels will ensure they are given the correct activity recommendation for their case.” We strongly disagree with the notion that the CDC’s pro-exercise advice constitutes “the correct activity recommendation” for us. Furthermore, we think it’s presumptuous and dangerous for Pandora to talk about “how much and what activity a person **should** do” (our bold). Externally imposed activity can cause permanent physical damage to the severely ill.

It is disheartening that the president of Pandora declined to amend its document to reflect reality, though many severe patients asked her to do so. Pandora does *not* speak for us on this matter. We ask you to disregard that section of Pandora’s letter.

Better Treatment Guidelines for Severe Patients

Activity

Severe ME patients absolutely must remain within our energy envelope, to prevent further worsening. We should increase our activity level only when our energy envelope expands; we must not push out of the envelope to meet some deadline imposed by a graded exercise or activity program. Some of us are using every available drop of energy just to survive the day--to chew the food that is spoon-fed to us and to use the toilet, commode, or bedpan, with assistance. If we have additional strength, it must go to other basic ADLs, such as bathing and brushing our teeth, not to programs of deliberate exercise. Such exercise programs divert our energy away from necessary ADLs and make us even more dependent on others.

The International Consensus Primer for Medical Practitioners, written by dozens of distinguished experts, supports the primacy of ADLs: “...[T]he more limited the patient's energy, the more important it is to **prioritize** energy needs and **budget** its use...First priority is to conserve energy for the essential activities of daily living.”⁸

We also agree with the following statement, aimed at less sick patients, from the 2014 guidelines of the International Association for

CFS/ME (IACFSME): “Any exercise program should not take priority over activities of daily living.”⁹

We, the patients--not doctors, not the CDC--must determine how much energy we have, and how much of it we have spent in a given activity. As the International Consensus Primer says, “Patients must always be in control of the pacing and duration of any activity.”¹⁰ The Overview of Canadian Consensus Document echoes this sentiment: “Externally paced ‘Graded Exercise Programs’ or programs based on the premise that patients are misperceiving their activity limits or illness must be avoided.”¹¹ At no time should we have graded activity imposed on us.

Treatments

Because we lack even a single FDA-approved treatment, we must have access to existing therapies such as antivirals, antimicrobials, immunomodulators, mitochondrial treatments, intravenous saline infusions, nutritional therapies, and treatments for orthostatic intolerance. At the same time, physicians should respect our right to reject treatment, because many of us have experienced iatrogenic worsening.

We must have adequate management of sleep and pain. Some of us are in excruciating pain on a constant basis and/or go days at a time without sleeping at all.

Role of the physician

We need physicians who are able and willing to make house calls. By definition, the severely ill have extreme difficulty traveling to local doctors’ offices, let alone to distant ME specialists. Many of us have lacked rudimentary medical care for years because we cannot find a physician willing to sometimes come into our homes and provide medical care. Please take into account our frequent hypersensitivity to sound, light, color, movement, touch and chemicals/fragrances.

We need physicians who are able and willing to fight for sufficient home aide services for us, so that we can live in our own homes in the community instead of in nursing homes. This entails challenging

Medicaid and private insurance companies on our behalf. Some of us need an aide for at least 16 hours per day or even around the clock. In addition, we need physicians who will support our requests for subsidized housing and other services.

We need physicians who are able and willing to order assistive technology for us, such as wheelchairs (manual and electric), electric beds, stair lifts, wheelchair ramps or lifts, walkers, canes, bath lifts, reclining shower chairs and other devices to help us survive and perhaps improve.

Other medical professionals

We also need phlebotomists, optometrists, nurses, dentists, dental hygienists, and other healthcare professionals who are able and willing to make house calls. Some of us have lost our teeth at a young age because we have been unable to get to a dentist's office for basic care.

Our Requests

We ask for respect from the medical profession, many of whom have belittled or even mocked the impact severe ME has had on our lives. Doctors take their cues from government agencies like NIH and HHS, whose employees have expressed extreme disrespect and contempt for ME patients in documents obtained through FOIA requests.¹²

We ask for recognition from our advocacy groups. We are appalled that the CAA refused to acknowledge Severe ME Awareness Day on August 8, despite many requests from patients.

We ask for basic civil rights, such as freedom from forced commitment to psychiatric institutions. The sickest patients are at the highest risk of having our rights violated in this way. For example, Karina Hansen, a young Danish woman with severe ME, has been held against her will for nearly two years in a psychiatric hospital.

We ask to receive medical care and caregiving services in our own homes, rather than institutions. This is our right under laws such as

the Americans With Disabilities Act, upheld by the Supreme Court's Olmstead decision.

Finally, we ask to be included in research studies. The discriminatory practice of designing studies to exclude the sickest patients must stop! Researchers need opportunities to focus on the more severe patients, who have the most developed phenotype/pathology.

Thank you.

Sincerely,

Rebecca Bailey
Sick since 1994
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Laurel B.
Sick since 1996
United States

Ricky Buchanan
Sick since 1994
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Linda Crowhurst
Sick since 1994
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cc:

Sylvia Burwell, Secretary of Health and Human Services
Dr. Francis Collins, Director of NIH
Dr. Thomas Frieden, Director of CDC
Dr. Elizabeth Unger, Chief of Chronic Viral Diseases Branch, CDC

¹ Bell, David S. *The Doctor's Guide to Chronic Fatigue Syndrome: Understanding, Treating, and Living with CFIDS*. Reading, MA: Addison-Wesley Pub. Co., pp. 122–123.
An online copy of the Bell Disability Scale is here:
<http://users.snowcrest.net/soza/DrBell.htm>

² U.S. Centers for Disease Control and Prevention. *Chronic Fatigue Syndrome (CFS)*.
Modifying Exercises for Severely Ill Patients.
<http://www.cdc.gov/cfs/management/managing-activities.html>

³ Tucker, Miriam E. “Chronic Fatigue: NIH Literature Review Faulted,” *Medscape Multispecialty*, 17 Oct. 2014.
http://www.medscape.com/viewarticle/833428#vp_4

⁴ Abbot, Neil C., ME Research UK, “Severely overlooked by science – an overview of research on severely-ill people with ME”
<http://www.meresearch.org.uk/information/publications/severely-overlooked-by-science/>

⁵ Unger, Elizabeth. Centers for Disease Control and Prevention. Conference call, 10 Sept. 2013.
<http://www.cdc.gov/cfs/meetings/cfspcoca-09-2013.html>

⁶ The CFIDS Association of America (CAA) recently changed its name to Solve ME/CFS Initiative.
<http://solvecfs.org/>

⁷ Chapo-Kroger, Lori. Letter to Institute of Medicine Committee on Diagnostic Criteria for ME/CFS. “Needs of Severely Ill in Creating a Diagnostic Criteria for ME/CFS.” 22 Jan. 2014
http://www.pandoraorg.net/uploads/Severely_ill.pdf

⁸ Carruthers, B.M. and van de Sande, M.I. et al, 2012, p. 15. “Myalgic Encephalomyelitis - Adult & Paediatric: International Consensus Primer for Medical Practitioners,” p. 15.
http://sacfs.asn.au/download/me_international_consensus_primer_for_medical_practitioners.pdf

⁹ Friedburg, Fred and members of the IACFS/ME Primer Writing Committee. “ME/CFS: A Primer for Clinical Practitioners.” 2014 Edition, p. 21.
<http://www.iacfsme.org/LinkClick.aspx?fileticket=zYEzLn11Ej0%3d&tabid=509>

¹⁰ Carruthers, B.M. and van de Sande, M.I. et al, 2012, p. 15.
http://sacfs.asn.au/download/me_international_consensus_primer_for_medical_practitioners.pdf

¹¹ Carruthers, B.M. et al. “Overview of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Guidelines, A Consensus Document,” p. 12. *Journal of Chronic Fatigue Syndrome* 11(12):7-115.
http://www.ahmf.org/me_cfs_overview.pdf

¹² Burmeister, Jeannette. *Thoughts About M.E.* “P2P FOIA Documents – Part I,” 19 Oct. 2014. (Also see Part II, Part III, etc.)
<http://thoughtsaboutme.com/2014/10/19/p2p-foia-documents-part-1/>