

January 22, 2014

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

Re: Important points to remember during the study



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## Needs of Severely Ill in Creating a Diagnostic Criteria for ME/CFS

As you consider creating or confirming a diagnostic criteria for myalgic encephalomyelitis /chronic fatigue syndrome, we want you to give consideration to the severely ill. Often these individuals are housebound or bedbound and thus invisible to the public's eye. If they do make a doctor's appointment, the doctor doesn't see the suffering they experience on other days.

A 2009 study in the United Kingdom showed that approximately 25% of ME/CFS patients are largely housebound or bedbound. That study was conducted by Buckinghamshire New University and National ME Observatory and their conclusion seems to hold true in other countries.



Ben DePasquale, before and after. Second photo is him at age 22, when a WHAM 13 news report that said: "Ben is almost completely bedridden. On a good day, he can take a few steps with a cane. At 6'2", he's down to 118 pounds. He need others to wash his hair and cut his food. In 2010, he left the house just twice."



Laurel Bertrand, before and after. Second photo is her video testimony to the Chronic Fatigue Syndrome Advisory Committee in 2009. She can only speak in a whisper. She only takes sponge baths.

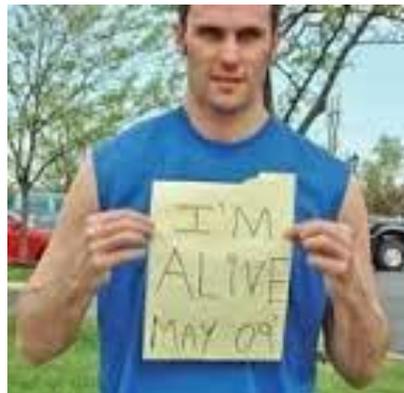


Amberlin Wu in her mid-30s undergoing experimental treatments in a hospital in 2010. For months, she had been unable to stand without falling, and then she developed shingles. The treatment caused headache, nausea and an exacerbation of light and sound sensitivity. But she did it because she was grasping at any hope. She died within two years.



Stephen Pagenetti at about age 18 when he was featured in the movie "I Remember Me." The narrator said, "He hadn't been able to sit up, stand without passing out or even eat on his own for two years.

The only way Stephen was able to attend his high school graduation was in a hospital bed and being transported and monitored by paramedics.



Mike Dessin after his recovery and when he was severely ill. At his worst, Mike had pancreatitis, could only lift his head a few inches, weighed 102 pounds at a height of 6'3", heart failure and a collapsed lung. He had to stay in a pitch black room and any touch was too much stimulation. He was diagnosed with chronic fatigue syndrome as the cause.

We show you these images and tell of their condition so you know there are differing levels of disability in ME/CFS that are not identified in most of the existing definitions. Some other diseases have stages or levels that inform the clinician of appropriate treatments. This is needed in this disease.

### **Disease Tests:**

A way to identify the severely ill is important so the physician knows what tests can be tolerated. The 2-day cardio pulmonary exercise test is becoming known for its ability to objectively measure the post-exertional neuro-immune exhaustion that is a hallmark of this disease. However, for the severely ill, this test may not be appropriate because they would not be able to complete the test, especially two days in a row. This does not mean they don't have post-exertional neuro-immune exhaustion. But in their case,

just brushing their teeth may bring days of relapse. An objective test and that does not require the severely ill to do activity that will bring them harm would be ideal.

### **Treatment Recommendations:**

Additionally, a way to measure the level of severity is important to knowing how much and what type of activity a person should do. "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," says the Centers for Disease Control Prevention in reference to activity level for the severely ill. A more moderately ill person may need to do 30 minutes of housework a day. A more mild case might be recommended to work part time with some accommodations. A way to identify those in different levels will ensure they are given the correct activity recommendation for their case.

### **Disability Assessment:**

It's hard to imagine someone who is bedbound and unable to feed themselves for days at a time must struggle to get disability benefits. But this does happen with this disease. This is because of misperceptions of the nature of the disease that the name causes and physician lack of knowledge. It's also due to the relapsing and remitting nature, "push –crash," experience so that occasionally a person looks well, even though they may end up in a relapse for days or weeks just from one outing. It's also because the severely ill are largely invisible to the public, even doctors.

Identifying those severely ill will not only help educate physicians, but it gives a basis for those severely ill to more quickly receive disability benefits, which is needed not only for income but continued health insurance.

### **How it's done in other diseases:**

For precedent, you might consider these examples:

- Acute leukemia and chronic leukemia
- Cancers with or without distant metastases or inoperable, unresectable or recurrent
- Breast cancer either inflammatory or not
- Alzheimer's either early onset or not
- Multiple sclerosis either malignant or relapsing-remitting, primary-progressive, secondary-progressive or progressive-relapsing

Most of these have objective measures, such as the level of blood markers, extent of damage in the body or likelihood of improvement or rate of progression.

**What We Recommend:**

Ideally we think three or more levels or stages of the disease should be developed and included in the diagnostic criteria. Ideally, an objective measure of these levels should be identified and included in the criteria.

Sincerely,

A handwritten signature in cursive script that reads "Lori Chapo Kroger".

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