

Public Comment
Lori Chapo-Kroger

Dear Nancy Lee, CFSAC Chairman and other CFSAC Members:

My name is Lori Chapo-Kroger, president of CFS Solutions of West Michigan. One of our goals is to ensure that healthcare providers are educated with correct information to change any bias about ME/CFS that affects patient care. This is the reason we endorsed the Request for Action Letter from the ME/CFS community and are requesting a meeting with key players across the DHHS. I would like to expand on why educating medical providers is urgently needed. Recently, members of the ME/CFS community stumbled across an online forum called Crass Pollination where people were ridiculing and making crass remarks about a child with ME/CFS and her mother.¹ It began with someone inquiring whether ME/CFS was biological or psychiatric in nature.

“Often it's a mother daughter thing starting off with the daughter suffering from some postviral fatigue.... they get so much attention and loving care that produce more dramatic stuff to keep that situation going.”

“...if "I can't cope with my life, I'll go become an infant." “Do these folks really die if they aren't coddled?”

“Last thing we need are people showing up with "CFS flare-ups" needing IV fluids and admission. We already have enough young people on too many meds and too much in the medical system. Come the f###k on.”

“ME could be a kind of folie à deux.” (Wikipedia: a psychiatric syndrome in which symptoms of a delusional belief are transmitted from an individual to another.)

Obviously, as seen by these remarks, the consensus of the doctors and nurses on this forum is that ME/CFS is a psychiatric condition. Granted, this site is a place where healthcare professionals with a sick and obviously crass sense of humor go blow off steam, but it demonstrates the mindsets of most medical providers.

One would think this abusive manner only happens behind the anonymous nature of a forum, but sadly, this happens in person, too. I am a nurse who used to work in ICU, and I would hear co-workers talk about how dramatic people with fibromyalgia and other neuro-endocrine-immune disorders behaved. These colleagues believed chronic fatigue syndrome is not a real medical condition and patients fake and exaggerate their symptoms.

Unless patients are fortunate enough to have an expert ME/CFS doctor, they often receive inadequate medical care based on biased thinking. Pediatric and adolescence patients have an especially difficult time because schools and physicians believe the child has a school phobia.

The following true stories demonstrate how common this mindset is in both primary and allied health care settings:

A robust teenager suddenly developed the flu, but it wouldn't go away. For two years she desperately tried to attend school, but the activity of a shower and getting ready wore her out. She would become light headed, nauseated, tachycardic and was very weak. The school threatened the parents with truancy, and the pediatrician scolded them for allowing her to stay home. When the parents asked the pediatrician if the daughter might have chronic fatigue syndrome, the reply was, no. The pediatrician was abrupt and told the teenager that there wasn't anything wrong with her and to quit faking her symptoms. She then callously turned to the mother and said, "Your son turned out just fine, but I don't know what you did to her?"

Blame was placed on patient and parent.

Early in her pregnancy, a woman had severe morning sickness and became dehydrated and malnourished. Because her electrolytes were off, she was also delusional, weak and had trouble forming sentences. Being the last patient of the day, her OB/GYN faxed paper work and sent her to the hospital to be admitted through the emergency department. Once the ER and on-call OB physicians discovered she had a diagnosis of chronic fatigue syndrome, their attitude toward her changed. She was left in the hallway for over seven hours receiving IV fluids with added potassium. During this time her labs began to improve, but her physical symptoms did not. They believed that her symptoms were psychological in nature and refused to admit her in spite of having orders from her personal doctor. She was too weak to advocate for herself and was still vomiting when she was sent home. A pregnant, disabled patient was abandoned because of an unspoken stereotype. Thankfully, she was admitted the next morning for a 6-day stay.

Do you see a pattern? Patients are routinely disregarded. There is a biased belief system that distorts clinician behavior and alters clinical assessment directly affecting patient outcome.

This type of corrupt judgment and disgraceful behavior is appalling and goes against everything the healthcare profession is supposed to represent. CFS Solutions of West Michigan believes ME/CFS patients should be treated with respect and have the same access to health care as patients with other prevalent diseases.

The Department of Health and Human Services must undertake a strategic, coordinated, and fully-funded effort to meet the critical need for adequate ME/CFS research, treatment and provider education.

Unfortunately, the CDC and other governmental agencies have contributed to this discriminatory philosophy. Past CDC policies and verbiage were not clear and lead to these erroneous conclusions by medical personnel and lead to the mistreatment of patients.

The Centers for Disease Control and Prevention website is where providers go for education. The CDC made positive changes on their webpage that reset the tone as recently as May 12, 2012.² CFS Solutions of West Michigan is grateful that under Dr. Elizabeth Unger's leadership, changes have begun to occur. However, there is still opportunity to improve specific diagnostic and treatment recommendations.

More troubling, the toolkit remains inconsistent with these website changes, and the educational courses are outdated.

Simply, the toolkit needs go. Too much emphasis is placed on CBT and GET and this contributes toward the misunderstanding of this illness. It reinforces incorrect ideas that CFS is psychological. Because of inconsistency on the website, physicians are confused on how to prescribe GET. A recent journal advises clinicians to prescribed aerobic exercise five times a week driven by duration in time instead of by physical symptoms.³ Meanwhile, patients are being harmed.

Much more encouraging is the recently released IACFS/ME ME/CFS Primer for Clinical Practitioners, based on the Canadian Consensus Criteria.⁴ This primer far surpasses anything available for clinical use and the one CFS Solutions of West Michigan will distribute. We recommend that the CDC adopt the IACFS/ME primer as its new baseline and collaborate with international ME/CFS experts and patient organizations to refine it over time and to proactively educate the medical community.

Another cause of medical professional ignorance and misunderstanding is the inappropriate classification of CFS by the National Center for Health Statistics department of the CDC. To correct this problem the Coalition 4 ME/CFS submitted a proposal that supported eight years of CFSAC recommendations to reclassify CFS as neurological as it is in the World Health Organization ICD-10.⁵ However, the director of the NCHS has not followed his own policy. One again, the ME/CFS patients and ME/CFS experts, that's you, are being disregarded because the NCHS guidelines on their website states that a decision was to be made before January 1, 2012. Yet, we have not heard anything, and emails and phone messages are rudely ignored.

The Department of Health and Human Services is the one organization positioned to provide the leadership needed to undertake a strategic, coordinated and fully-funded response to the challenge of ME/CFS. As one of the organizations signing the Joint Call to Action Letter sent to Secretary Sebelius, CFS Solutions of West Michigan looks forward to scheduling and meeting with key representative from across the DHHS to further discuss educational concerns and formulate a comprehensive plan.

In health and hope,

Lori Chapo-Kroger, RN

References

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