

A STATEMENT TO THE CFS ADVISORY COMMITTEE

FROM: Catherine Morgan -- I am a 40 year-old patient with CFS, a mother, and a nurse (although unable to work as a nurse due to my medical problems).

Although, I wish I had been able to attend this meeting in person, I am extremely grateful to have the opportunity to submit this written statement.

Being a single mother is not easy under any circumstances, but being a single mother with Chronic Fatigue Syndrome has been particularly difficult. I have been suffering with this insidious cluster of debilitating symptoms (referred to as Chronic Fatigue Syndrome), for over ten years. But it has only been more recently that I have come to accept that this condition isn't going away. The funny thing is, even though I am caught in the middle of mourning for the person I might have been, and accepting the person I am, I've begun to feel hopeful. Hopeful because, by letting go of the burden of needing to be cured, I am also letting go of the idea that if I just got more sleep, or got more exercise, or took the right combination of medications, or found the right doctor, that somehow I would be better. This thought process is exactly what keeps someone with Chronic Fatigue Syndrome down. It puts a judgment on them, that they are somehow responsible and this is not true. So, letting go of this type of destructive thinking is half the battle with this disease. And I think that is why this type of awareness (that is being done here today) is so important.

I believe we can all agree on the importance of research so that a diagnostic tool can be found, and a treatment developed. However, what is equally important, but continues to be overlooked, is the acceptance by doctors that this is a "real" medical condition and not an "emotional" problem.

Are many people with Chronic Fatigue Syndrome depressed? Of course they are. Anyone suffering from a chronic debilitating medical condition, is most likely going to have some degree of sadness, anxiety, or depression associated with it. A physician wouldn't dream of telling a patient with Lupus that depression is the cause of their disease, but surely there are many patients with Lupus that are also depressed. And by all means depression, whether associated with Chronic Fatigue Syndrome, or any other medical condition, needs to be addressed and treated. Depression is a symptom associated with this disease, not the cause of this disease. By "blaming" this disease on depression, or any other "emotional" disorder... Well, that is simply "blaming" the patient for their disease, and that couldn't be farther from the truth.

The truth is, doctors become doctors for the same reason I became a nurse, so they can help people. And, I think doctors feel helpless when they have a patient that they can't "fix". Herein lies the problem. Patients can not, and should not have to WAIT to receive compassion and treatment from their doctors, until scientific research has found a way to cure them. Just as I have come to accept my condition, doctors must come to accept this condition and treat the patients and their symptoms accordingly.

There is so much a doctor can do to help a patient with Chronic Fatigue Syndrome. The most important is to accept them and their diagnosis. Don't tell them you don't believe in the diagnosis. What purpose does that serve, other than to degrade them? Second, do not pass judgment on the patient for their condition. Treat patients with Chronic Fatigue Syndrome the same way you would treat anyone else with a chronic medical condition, with respect and dignity. We are not just patients with Chronic Fatigue Syndrome, we are human beings. Third, work together with the patient to address the specific symptoms of their disease. It doesn't matter what you call this disease, a physician CAN treat the patient and their symptoms regardless of what the name of the disease is. A physician CAN treat the patient and their symptoms regardless of whether research has found a cause or cure for the disease.

These are simple things, that could be implemented right now. Today is what matters to us. Today is all any of us have. Help us get through today, then tomorrow, and then help us take one day at a time towards being as well as we can be, given our disease. If you can do that, you will be making a huge difference in our lives... Anything less, is tantamount to "doing harm". So please - Do No Harm - that is all I ask.

Thank you.
Catherine Morgan
Livingwithcfs.wordpress.com