

Hi my name is Mike Dessin, I've had Myalgic Encephalomyelitis for 14 years, a disease that is unjustly named Chronic Fatigue Syndrome in the U.S. I had one of the most severe cases of ME/CFS ever recorded, with subsequent remission.

At the worst stage of my illness, which was about a year ago, I suffered beyond what most humans can comprehend.

I was completely bedridden and unable to lean up more than a few inches. I was unable to read, write, understand words when spoken too, or complete a thought process. Even a bit of thinking would hyper stimulate my nervous system too much. I had severe dementia. I couldn't see the walls around me. Neurological dysfunction too obscure to put into words. In the last month before my recovery I was unconscious an estimated 90% of the time, not sleeping but literally unconscious. I was basically comatose.

I'm nearly 6'3, and last December I weighed 102 pounds. I had heart failure, severe pancreatitis and my lungs collapsed. My body was producing just enough energy to sustain a heartbeat.

To make things even worse, I was confined to a pitch black room isolated from the world. Unable to tolerate the slightest bit of light or noise much of the time. I had sensory overload so bad, I couldn't be touched, as it was too stimulating. The consequences of being over stimulated resulted in further exhaustion and seizures.

In addition, I had EXTREME chemical and Electromagnetic Magnetic Frequency sensitivities. Needless to say, I had to be in a very special environment to stay alive. It is painstakingly difficult to care for someone in the condition I was in.

I was as sick as an end stage AIDS and MS patient put TOGETHER. Immune deficiency similar to what an AIDS patient presents and more nervous system abnormalities than most MS patients. But I don't have MS or AIDS. I have a disease called Chronic Fatigue Syndrome, which merely describes a symptom these diseases share.

I was left for dead; I was left withering away in my dark room. I was left to die due to the extreme lack of knowledge, compassion or regard by our medical community.

I had spent 10 years searching for help from doctors. I would hear, oh it's JUST allergies, it's JUST chronic Epstein Barr, it's JUST depression, oh it's JUST chronic fatigue syndrome and there is nothing we can do.

In the fall of 06' I fell down in a hotel lobby in New York, I was suffering from CFS related exhaustion. My dad called 911 and the ambulance came to pick me up. On the way to the hospital, I told the tech "I had severe exhaustion and I had Chronic Fatigue Syndrome," some know the disease as Myalgic Encephalomyelitis. The tech said there was no such thing as Myalgic Encephalomyelitis.

When I arrived at the hospital they said my vitals were normal and they put me in the psychiatric unit. I spent 24 hours there, where I was strip searched, repeatedly questioned about my personal life and given a cocktail of psychiatric drugs. Shortly after, I went into my last relapse that would nearly end my life.

Now who's to blame for all of this? Clearly this disease and its millions of sufferers have been shortchanged in an EPIC way over the last 20 years by the government, medical community and the public at large. There has been a false stigma attached to the disease created by lack of research and inaccurate information disseminated by the CDC.

One major cause in this disease not getting the proper recognition stems from the naming and definition. The CDC wrongly changed the name of Myalgic Encephalomyelitis to CFS, in an attempt to undermine the serious nature of this disease, in favor of politics and economics.

In saying that, I am just one of thousands upon thousands of ME/CFS patients who are currently suffering near the extent I was. The only difference, they most likely won't live to share their experience, unless things change. Many ME/CFS patients succumb to cancer, heart failure, pancreatitis and other co-morbid conditions that come along with having this disease. Many will die from suicide, committing suicide at a rate, double that of MS patients.

They are not committing suicide because of depression or stress. They are committing suicide for multiple reasons which include.

Suicide from decrease in quality of life, created by this disease. Their committing suicide because, the medical community, family and friends, don't understand what is happening to them, and there is little hope for a cure.

They are committing suicide because they can't bare the extreme physical and neurological dysfunction. They are committing suicide because many of them are inundated with toxic poisoning. They are committing suicide because they have dozens upon dozens of infections that human beings are not supposed to get. Their committing suicide because they have no safe place to go, no special facilities that have staff trained to care for ME/CFS patients. No special facilities that are free of chemicals or sensory stimulus. These patients have NO WHERE TO TURN.

So while these patients are being suffocated by toxins and destroyed by viruses, suffering greatly, the CDC's answer, let's spend money to research the effectiveness of cognitive behavioral therapy and graded exercise therapy.

I'm alive and speaking to you today because I got proper treatment. A treatment that focuses on the true biomedical basis of this disease rather than the MYTHS created surrounding this disease.

Myths, such as treating this disease with cognitive behavioral therapy (CBT) and psychological intervention should be primary treatments and coping mechanisms. As well as using Graded Exercise Therapy for increased exercise threshold. These therapies do not even come close to a real cure and can be extremely dangerous UNLESS they are integrated into a therapy that addresses underlying issues.

I realize that this is the easy way out for Reeves and his side kick Simon Wessley in the U.K.. If we think this is an effective treatment, why do I speak with thousands of ME/CFS patients who feel differently? Why is there no person in this room with true CFS .....who has been helped by these therapies?

Why have ME/CFS patients died from extreme relapses brought on by these therapies? They die, because if done at times where they have difficulty processing information, cognitive input can put them into extreme relapse. Yes, it actually progresses the disease. They die because they think graded exercise is beneficial. In reality, exercise in many cases can lead to further damages to their body and a downward progression of the disease. Yes, pacing is a good thing, and that is what ME/CFS patients should do....on their own terms.

Blaming stress and depression instead of looking for a legit biomedical explanation of this disease seems to be another easy way out for the CDC. It's highly unlikely ENTIRE outbreaks have been caused by stress and depression. Entire towns just suddenly get ME/CFS because they're stressed and depressed. Truth is, due to abnormalities in the nervous system brought on by this disease, stress or depression can cause disease progression, just as with most other diseases.

You've been listening to patient testimony for years, If you really thought this is a serious issue, why do most doctors still have no idea what CFS is, and many have never heard of ME.

Why have government funds for the study of this disease dwindled over recent years?

Why is this disease not taken serious by our researchers?

Why do our peers not take this disease seriously?

Why hasn't the name chronic fatigue syndrome been changed, to accurately reflect the nature of this disease?

Why does the U.S have the most watered down definition of Chronic Fatigue Syndrome?

Why are there no facilities equipped to take care of severely ill ME/CFS patients?

Why are patients not covered by insurance when they seek the help of alternative minded doctors, when these doctors are the ones saving the lives of ME/CFS patients?

These issues still remain, because they solely reflect what you are NOT doing for our community.

I nearly lost my life, and many others are suffering and will die prematurely, if we all don't step up, and do the right thing.

It's time for a New Day to begin