

Testimony for the CFSAC Meeting Oct '09

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Thank you for the opportunity to contribute to the CFSAC meeting. Though I have spent the last five years doing a substantial amount of research on Chronic Fatigue Syndrome (CFS), and I do include a few references in what I am about to write, I have not had the time or energy to prepare a truly academic type of presentation. That is due to the fact that I have CFS and am very limited in my capacity to function with any endurance. However, as issues concerning CFS are extremely important to me, I consider it vital to contribute to this meeting. Therefore, in this paper, I am predominately speaking from the heart, from personal experience, and from the many online conversations I have had with other members of the CFS community, as well as from the research that I have retained in my memory. Much of what I have to say was actually written to address comments that were posted to an online newspaper in response to the discovery of the retrovirus XMRV. I feel that they are valid for purposes of this discussion, as well, though, because many of the comments that I was responding to were representative of the things that those of us with CFS hear all too often. They are representative of the stereotypes that much of the general public and sadly, too many doctors, have of us. They are comments that have arisen from the spread of misinformation, the attempts to say that CFS is all in our heads, or another form of depression, malingering, or just pure laziness.

This is inaccurate and has been due, in large part, to the empirical definition of CFS and due to the name CFS itself. Further, the empirical definition has given rise to research that studied groups that do not truly represent the patient population. The current definition does not even include post exertional malaise (PEM) as primary diagnostic criteria. Someone who does not have PEM could be diagnosed with CFS, even though any true CFS patient will tell you, it is a key feature of the illness. PEM is included in the Canadian definition of CFS, which is the definition that the majority of patients have been practically begging for the US to adopt for quite some time now. The Canadian definition is much more specific to the population that the Center for Disease Control (CDC) claims to be studying, and as such, it eliminates many of the other illnesses that inadvertently get included in the current definition and that skew the results. (One recent study by Leonard Jason showed that 38% of the people who get included in the current definition of CFS actually have major depression and not CFS at all, and it is quite clear, even without another study saying so, that such an inclusive definition also winds up falsely counting many other fatiguing illnesses.) This does a disservice to patients who do have CFS, as well as to the patients who have other illnesses and are mistakenly included in these studies. It is also a huge waste of time and money.

In addition to adopting the Canadian definition, the majority of patients strongly desire a change from the name CFS. Not only does the current name trivialize the illness and give rise to misunderstanding, but it fails to address so much of what the illness really entails. So many of us have been told, "Oh, I get tired too," and have heard other far more hurtful statements generated in response to being told that we have CFS. The name gives the impression that we are just a little tired. It does not even begin to express the magnitude of utter exhaustion that we feel, nor does it relate the variety of other, often disabling symptoms that are common to CFS. This impression is not limited to the public, either. Doctors and other medical professionals also often react poorly, just based on the name.

I have seen this played out in my own life many times. However, lest my experiences with this seem too subjective, I can refer you to a study conducted by Jason Leonard. (see reference # 3) He found that among medical students and residents, simply changing the name to something more medical sounding and significant brought about a change in the prognosis and the way they viewed the illness. These are people who should be able to evaluate illness based on clinical findings and symptoms, not on a name, so is it any wonder that the general public reacts as it does to the name CFS? Many other countries, as well as the World Health Organization (WHO) have recognized this illness as Myalgic Encephalomyelitis (ME), and many patients would be satisfied with that name. Even the combination ME/CFS that is getting increasing use would be a huge improvement. Continuing to use the term CFS is analogous to calling diabetes; a minor sugar sensitivity, cancer; a few fast growing cells, or MS; a little balance problem. Obviously, such names would be ludicrous in their failure to portray anything close to a complete picture of these illnesses. Yet, that is exactly what has been done by giving us the name CFS.

The rest of this paper contains the comments that I wrote in response to an online newspaper article. In addition to being relevant for the reasons that I previously mentioned, I also believe that my comments are significant because they address statements that citizens in the UK were writing. (The newspaper I am bringing up is a UK paper. I do not have the reference to it listed, because I did not wish to hang onto such a distressing and inaccurate article, and I had not originally planned to use it for this CFSAC meeting.) The statements I refer to clearly expressed misconceptions that the UK has about CFS, misconceptions that have arisen as a result of the UK's national healthcare system's views on CFS. The newspaper comments that I responded to also brought up concerns of those who do not have CFS, but do have mental illnesses. Some of that group were upset, because they felt that CFS patients have been trying to distance themselves from mental illness due to a stigma associated with such illnesses. They believe that our attempt to separate CFS from mental illness is making the stigma worse for them. Others brought up information about the UK's use of Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET) as the only treatments for CFS. Given that Dr. Reeves has expressed his

admiration of the UK's treatment protocol, and given that he continues to collaborate with Peter White, and seems to want to model the US treatment protocol on that of the UK, I believe that my comments are quite pertinent to the current meeting.

This is what I wrote to the newspaper (I used the term ME, because that is how the majority of people writing were referring to it):

As one who has struggled with depression and PTSD and who became a counselor after recovering from both, I understand all too well what it is like to have a mental illness. Despite the stigma, I have no problem sharing what I have been through with others. I also believe very strongly in the power of counseling, including CBT.

I have often wished that ME was a form of mental illness, because if it were, there would be more of a possibility of truly getting well. I can also tell you that when I struggled with mental illness, people were *more* compassionate towards me than they have been with ME. From what I have seen, the stigma associated with ME is worse than that associated with mental illness (and no, I am not downplaying the way that people with mental illnesses are often treated. I think it is horrible and undeserved. I am just relaying my own experience.)

The reason that I do not want to be told that this is depression or some other form of mental illness, is that it is not. Insisting that it is, has led to treatments such as CBT and GET being used as the only treatments, and that has not only not helped, but has actually harmed many. And, it has not led to other, more effective treatments being found.

If people with cancer, AIDS, or MS were constantly told that they had mental illnesses and were limited to treatments like CBT and GET, no one would question their frustration. No one would say that they were just afraid to be stigmatized and were causing those with mental illnesses to be further stigmatized in the process. That has nothing to do with a desire to "distance themselves" from mental illness, as someone wrote here. It has everything to do with wanting to find effective treatments so that they can get their lives back.

That is exactly how ME patients feel. We have nothing against people with mental illness, and we can empathize with how they are treated. However, those feelings do not change what we have, nor will they make CBT any more effective for treating ME. CBT is effective for helping people to cope with having a devastating physical illness, but using it as a treatment for that illness itself is not effective and is seriously hampering the search for more effective treatments.

Before getting ME, even when I was depressed, and more so when I had recovered from it, I had a much, much fuller, busier, more active life. I worked full time, went to school full time and got

almost straight As, went to church, had an active social life, spent time with my family, and was very active physically. Among other things, I trained for and ran full marathons. I absolutely loved doing them. I also did things like sky diving, traveling, going to museums and aquariums, and photography. I had hopes for a family and plans for a career spent helping others.

ME has taken all these things and more from me. I did not stop doing them because I am depressed. I *am* very sad that I can no longer do them. I did not stop doing them because I had "irrational illness beliefs" and mistakenly thought that doing very little would help. *On the contrary*, I tried to continue them as long as I possibly could, and that made me keep getting sicker. I only backed off when my body absolutely would not let me do them anymore. I did not stop exercising as I used to because I was afraid of exercise. I *am* afraid, very afraid, that I will not be able to do those things again. Running especially has brought me joy for 26 years. It kills me to think that I may never be able to run again. I miss running tremendously. I miss my life tremendously. I want that life back.

References:

1. Carruthers, Bruce M & van de Sande, Marjorie I. *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners: An Overview of the Canadian Consensus Document 2005*.
http://www.mefmaction.net/Portals/0/doc//Canadian_ME_Overview_A4.pdf
2. Jason LA, Najer N, Porter N, Reh C. "Evaluating the Center for Disease Control's Empirical Chronic Fatigue Syndrome Case Definition. *Journal of Disability Policy Studies*. 2008.
3. Jason LA, Taylor R, Plioplys S, Stepanek Z. "Study Compares Medical Trainees' Reactions to Three Names for CFS." *The CFIDS Chronicle*. July/August 1999. Also: "New Chronic Fatigue Study Fuels Debate on Name Change; DePaul Professor Says Biological Name Taken More Seriously." *PR Newswire*. August 26, 1999. <http://www.prnewswire.com>
4. Reeves WC, Wagner D, Nisenbaum R, Jones JF, Gurbaxani B, Solomon L, Papanicolaou DA, Unger ER, Vernon SD, Heim C. "Chronic Fatigue Syndrome – A Clinically Empirical Approach to Its Definition and Study." *BMC Med*. December 15, 2005.
5. http://www.ipetitions.com/petition/empirical_defn_and_CFS_research/index.htm

For I am convinced that neither death nor life, neither angels nor demons, neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation, will be able to

separate us from the love of God that is in Christ Jesus our Lord.
Romans 8:38-39