

Hello. My name is Barbara Bell. I live in Manassas, V A. Thank you for this opportunity to speak.

I'd like to talk about the emotional and sociological effects of Chronic Fatigue Syndrome. Health care practitioners, particularly those in mental health, need more education in this area.

CFS leads to profound loss. It can make or break a marriage. Sick parents may lose custody of their children. It often leads to career death, financial insecurity and an uncertain, scary future. Friendships lapse because we can't keep up with them or illness makes them uncomfortable. We may have to give up pets. We may lose our independence. Self esteem, self worth and self respect are shaken. Our self identity is challenged. Depression often follows. People with CFS almost always suffer protracted grieving that may last for years because all of the losses we experience are compounded by physical misery. We may not all experience the exact same losses, but we all grieve our former lives. We grieve being able to take energy and health for granted. We grieve being able to go out with friends or do anything else extracurricular. Sometimes even talking to a friend on the phone takes more energy than we have.

We become frustrated and angry with our limitations. We push beyond our limits because we don't want to accept our losses. We blame ourselves for not trying hard enough or in the right way. Many of us feel despair and even suicidal feelings at some point. Finances are a dark cloud hanging over most of our heads, especially those of us who are single, jobless, and praying that Social Security will move quickly and in our favor. We often have to forego treatment because we can't afford it. To add insult to injury, stress makes CFS symptoms worse. Everything I'm describing is extremely stressful. We're chronically stressed.

This illness is very isolating. Most people, including doctors and mental health professionals, have no idea how profound the effects of CFS are on our lives. Many don't believe it's a real illness. Certainly not a serious one. We're often told that we look fine or good or healthy. Some say that we're hypochondriacs or faking it. Lack of understanding leads to conflict with friends, family, bosses, coworkers, doctors and pretty much anyone we interact with. Loved ones feel slighted because we don't spend enough time with them. They become resentful when they have more chores to do than before. They feel helpless and guilty. *We* feel helpless and guilty. These negative emotions often come out as aggression or passive aggression.

Current education efforts focus primarily on physical symptoms and diagnosis. It's crucial that health care providers of all kinds understand the far-reaching effects of CFS on a patient's emotional well being. That's especially true for mental health providers, who are trained to help patients with coping and self esteem. But they can only do so when they're aware of the physical and psychological issues at hand. Physical and emotional well being are linked. Treating both will have a greater effect than just treating one. It's vital for patients to hear that they are believed, that it's okay to grieve, that what they feel is normal and expected, and that there's no shame in asking for help. We encounter so much invalidation that a little bit of validation can go a long way.

Thank you for listening.