

25 Random Things about CFS

provided courtesy of the CFIDS Association of America



Recently a networking activity called “25 Random Things About Me” swept through the online social networking site Facebook. It seemed like a great way to convey some important information about CFS to those who might be new(er) to it, so I published my own version on the CFIDS Association’s Facebook page and offer it here for you to print or forward to others. - K. Kimberly McCleary, President & CEO

1 Don’t be fooled by the name. CFS is more than just being tired at the end of a busy day or week. The impact of the illness has been shown in research studies to be equal to that of cancer, COPD and end-stage AIDS.

In addition to severe fatigue that’s not relieved by rest, the 8 “official” symptoms of CFS are unrefreshing sleep, muscle pain, joint pain, headache, sore throat, swollen lymph nodes, cognitive impairment (trouble thinking clearly) and postexertional relapse. You have to have 4 of these 8 symptoms for six months or more to meet the research definition for CFS. There are many other symptoms that are common to CFS. You can find them on our website at www.cfids.org/about-cfids/symptoms.asp.

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3 As many as 4 million people in the United States have CFS. Chances are you know one or more of them. They often don’t look sick when they’re out in public, and when they’re not out in public, they’re probably at home recovering from their last trip into the world.

Women are more likely to get CFS than men, and adults are more likely to get it than kids. But make no mistake, it affects people of all ages, races and socioeconomic status. It occurs around the world in urban, metropolitan and rural areas. We still don’t have a complete answer as to why.

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5 While there is no simple diagnostic test, CFS can be diagnosed and treated. It takes some persistence on the part of the patient and the clinician, because other causes have to be ruled out, but it’s quite possible to do. If you get diagnosed and your doctor tells you, “I think you have CFS and that means there’s nothing I can do for you,” it’s time to find another doctor.

Managing the symptoms of CFS—usually beginning with treating sleep problems and pain—requires partnership with a health care professional. It takes some trial and error to find the combination of medications, supportive therapies and lifestyle adjustments to improve function and quality of life.

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7 The most profound and often best way to distinguish CFS from other conditions with similar symptoms is what’s known as “postexertional relapse” or “postexertional malaise.” This refers to a return of all symptoms after even minimal physical or mental exertion. Helping a child with homework, making a trip to the post office, preparing a simple dinner for the family are all things that can send CFS patients back to bed for hours, days or even weeks. This is often a huge contrast to their pre-illness capacity for activity.

If you haven’t done so already, I highly recommend you read Laura Hillenbrand’s moving personal account of CFS that was published in the *New Yorker* on July 7, 2003, “A Sudden Illness.” We won’t run afoul of copyright laws by posting it here, but it’s pretty easy to find online using any web-wide search engine.

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9 The CFIDS Association of America was established in 1987. Since then it has grown to be the largest and most active organization dedicated to conquering CFS. Learn about the Association’s work at www.cfids.org.

There are a lot of smart, dedicated people working to make progress in the understanding of CFS. I’m fortunate to work with hundreds of them through the CFIDS Association. There are also caring people working in lots of sectors, including government, who want to help. The Association helps facilitate those efforts too.

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11 CFS is complex. It has defied complete explanation for more than 20 years since it was first defined. It will likely take a multidisciplinary group of researchers, using cutting edge technologies and techniques to unlock its cause, treatment and cure. But I believe it can be done.

One of the worst aspects of CFS doesn’t show up on any list of symptoms or reports of research findings. It’s the isolation that’s a consequence of having a chronic illness that no one fully understands yet. Having to alter plans for the future, adjust your aspirations and set vastly different expectations is a constant challenge to patients and their family members.

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There are nearly 5,000 articles in the peer-reviewed medical literature about CFS. Every body system studied has revealed subtle abnormalities, although not every defect is present in every patient. As CFS science advances, critical insight is likely to emerge. It reminds me of a point in the history of MS in the 1970s, when it was called “hysterical paralysis,” just before MRI technology detected demyelination of the spinal cord.

If you want a quick synopsis of the 10 most important research findings about CFS, read Harvard Medical School expert Dr. Anthony Komaroff’s summary at www.cfids.org/about/10-discoveries.pdf. You might recognize Dr. Komaroff’s name; in addition to other distinctions, he’s a regular contributing editor to *Newsweek*.

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If you don’t have any idea what it feels like to have CFS, think of the worst flu you’ve ever had. Think about feeling that bad every day. Every day for a month. Every month for a year and so on. The average duration of illness is 10 years, but recovery is tough to define and most people report lifelong limitations of some degree.

Oprah has given CFS some attention by including it in a show about “hard to diagnose conditions.” Wilhelmina Jenkins and her daughter, Kamilah, were guests on the show and shared their experience as patients. That was in June 1998. Wilhelmina is still recovering from that trip to Chicago.

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The *New York Times* has validated CFS too. *Times* writer David Tuller wrote an article about CFS on July 18, 2007, that quite dramatically changed how CFS is treated by other reporters. You can read more about that at www.cfids.org/cfidslink/2007/100301.asp.

I would not wish CFS on my worst enemy. I want to see all the people who have CFS return to healthy, productive lives. Our world will be much richer when we have them back to full capacity.

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There are researchers all over the world who are studying CFS. The Japanese government has taken a serious interest in severe fatigue and supports a very well-organized team of investigators to study it. During a visit to their facility in April 2008, it was breathtaking to see how leadership, coordination and diverse scientific skill sets can create synergy. It’s our model for what we want the Association’s research program to be.

There is a United States federal committee for CFS, the DHHS CFS Advisory Committee, that meets twice a year. It gives us a vehicle to engage federal agency representatives and to hold them accountable for what they’re doing (or not doing) in research and education. Although working with the government has its share of frustrating moments, it is an important partner to involve in the effort to conquer CFS.

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CFS is definitely not the same as depression. Sometimes they occur together, but they are quite different even though some of the symptoms overlap. In CFS, levels of the hormone cortisol are typically lower than normal; in depression they are higher. When you have CFS, you want desperately to get back to the activities of your life. Depressed patients often withdraw from their lives, even if they push themselves to appear normal.

CFS costs the United States a lot of money. Every single year, CFS costs the U.S. economy about \$25 billion in lost productivity, direct medical expenses, disability payments and other costs. The U.S. government spends about \$10 million looking for better diagnostics and treatments. Too bad CFS isn’t a bank or automaker; it would be much easier to make the case for a “CFS stimulus package.”

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If what you’ve read about CFS sounds like something you, a friend or family member might be dealing with, seek medical care from the professional who knows you best. There are tools to help educate medical professionals about CFS. Check out info about our online Medscape course at www.cfids.org/cfidslink/2009/010704.asp. Take your doctor a copy of the *Toolkit for Health Care Professionals* at www.cfids.org/sparkcfs/2008/toolkit4.pdf. But start somewhere. The longer you go without appropriate symptomatic care, the longer you risk staying ill.

There’s a lot of information about CFS available on the world wide web. Always verify the source of the information and look for two sources that make the same statement. Especially when it comes to treatment, there are a lot of dubious claims made about products that haven’t been adequately evaluated. Take care!

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There is hope. Research is converging on answers and more scientists and doctors are getting involved in the search for better diagnostics and treatments. We can accelerate the momentum with your engagement and support! Visit www.cfids.org to learn more about CFS and to help conquer this illness.

Thanks for reading my “25 Random Things About CFS.” See the CFIDS Association’s Facebook page or web site to learn more about CFS and the Association’s work. Access this list online at www.cfids.org/cfidslink/2009/040109.pdf