

Research & Training Center on Independent Living

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What CILs Need to Know About People With Chronic Fatigue Syndrome

What Is Chronic Fatigue Syndrome?

Chronic fatigue syndrome (CFS), also known as chronic fatigue and immune dysfunction syndrome (CFIDS or CIDS), is a complex illness characterized by incapacitating fatigue, and muscle and joint aches, as well as other debilitating symptoms. It also may include problems with sleep and nerves, headaches, tender lymph nodes, weakness, and inability to concentrate. Cognitive symptoms may include memory loss, confusion, and spacey feelings. Those affected may feel too exhausted to participate in basic activities of daily living. They may become worse with exertion, and have little energy. Stress, whether physical, emotional or intellectual, can aggravate symptoms. As with any chronic medical problem, many persons experience anxiety and depression as a result of the limitations of being sick. CFS generally happens suddenly. Some people get better over time. Others never do.

What Causes CFS?

The cause is unknown. Studies have linked it to viral infections, chemical exposures, or environmental allergies, and traumas such as head injury. About 500,000 to 800,000 people in the United States have this condition.

What Accommodations Do People with CFS Need?

Not everyone with CFS needs accommodations, and some need only a few. Those severely affected may not be able to participate in activities outside their home. Some accommodations are: provide memory aids and written instructions; minimize distractions in the work place or home environment; allow breaks as needed to rest or sleep; reduce or eliminate physical exertion; reduce walking or provide a scooter; and allow the person to work or receive services from home. It is essential that the individual be allowed to use his or her own judgment in pacing activities. Emotional support is also vital because of the depressive and discouraging effects of CFS. The Job Accommodation Network lists further examples at <http://janweb.icdi.wvu.edu/media/ideas.html>.

What Are Important Advocacy Issues for People With CFS?

Many affected individuals are unable to get proper medical care because of doctors' unfamiliarity with research on CFS. CILs can help by gathering information from resources such as those listed at the end of this article and providing information to their consumers, board, and community. Many people with CFS would like the Centers for Disease Control and Prevention to change the name of the disorder to more accurately reflect the nature of CFS.

They feel the term "chronic fatigue" trivializes the disorder. Currently no consensus exists on what the disorder should be called. Used outside the United States, myalgic encephalomyelitis is one favored name possibility. Also, while access to Social Security disability benefits have increased for this population, many consumers still need advocacy in the application process because of continuing prejudice against CFS.

Where Can I Find More Information on CFS?

CFIDS Association of America, PO Box 220398, Charlotte, NC 28222-0398, (800) 442-3437, <http://www.cfids.org>. Besides a valuable Website resource, this organization offers the *Disability Workbook for Social Security Applicants* by Douglas Smith. This guide provides worksheets, tips on qualifying for benefits, and answers to frequently asked questions. \$20.00.

The National CFIDS Foundation, Inc., 103 Aletha Rd., Needham, MA 02492, (781) 449-3535, (781) 449-8606 FAX, <http://www.ncf-net.org>. Organization funds medical research and provides education.

<http://www.healingwell.com>. Site offers resources, message boards, chat rooms and the latest medical information.

CFIDS/Fibromyalgia Self-Help, 777 San Antonio Rd #121, Palo Alto, CA 94303.
<http://www.cfidselfhelp.org>

Hope and Help. Karyn Feiden, Prentice Hall Press, 1992. This 216-page book provides insight into the experience of having CFIDS, including the physical and emotional impact, difficulty in obtaining a diagnosis, and the key strategies for managing one's life.

A Clinician's Guide to Controversial Illnesses: Chronic Fatigue Syndrome, Fibromyalgia, and Multiple Chemical Sensitivities. R. R. Taylor, F. Friedberg, and L.A. Jason. Professional Resource Press, 2001. Useful and informative, this 165-page guide is for clinicians seeing people with CFS in their practices, and for advocates.

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