

Research & Training Center on Independent Living

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What CILs Need to Know About People With Fibromyalgia Syndrome

What Is Fibromyalgia Syndrome (FMS)?

Fibromyalgia literally means pain in the muscles and the fibrous connective tissues. FMS involves both muscular pain and fatigue and affects between seven and 10 million Americans. Evidence shows that fibromyalgia dates back centuries and has been reported throughout the world. Its cause is unknown but it is believed to occur when a triggering event such as a virus, infection, or trauma happens to the affected individual. Some research strongly suggests that FMS is a disorder of the central nervous system rather than the musculoskeletal system as originally thought. For FMS to be diagnosed, a person must have widespread pain for at least three months and a minimum of 11 out of 18 specified locations on the body that are abnormally tender.

How Does FMS Affect Individuals Who Experience It?

Individuals are affected differently and may have some or all of the identified symptoms. FMS causes fatigue and exhaustion in about 90% of those affected. Fifty percent of people with FMS also have chemical sensitivities. They may also have sleep disorders, recurrent migraine or tension-type headaches, impaired coordination, severe changes in mood and thinking, difficulty concentrating and remembering, digestive disturbances, and many other symptoms. Many with FMS also have Multiple Chemical Sensitivity Syndrome, Myofascial Pain Syndrome, and/or Chronic Fatigue Syndrome. These individuals are most likely to be significantly disabled with FMS.

What Accommodations Do People with FMS Need?

Not everyone with FMS needs accommodations. Those who are severely affected may not be able to function outside their home. Examples of some accommodations are: provide written instructions and reduced distractions, reduce physical exertion, provide ergonomic workstation design, allow periodic rest sessions, eliminate fluorescent lighting, implement a fragrance-free/smoke-free policy, allow flexible work schedule or telecommuting, and reduce noise. Individuals with FMS should be allowed to use their own judgment in pacing activities. Patience and understanding are important when dealing with any type of cognitive issues. Emotional support is vital because of the depressive effects of FMS. Input from those affected should guide any accommodation policies and practices. The Job Accommodation Network lists further examples of accommodations: <http://www.jan.wvu.edu/media/ideas.html>

What Are Important Advocacy Issues for People with FMS?

Typical FMS advocacy efforts focus on elevating the credibility of FMS among clinicians, researchers and funders. Many consumers struggle with difficulty obtaining a diagnosis, treatment, and acknowledgement from medical professionals, family members and friends, and employers. Fibromyalgia pain is often dismissed as psychological or not real. This population generally is not included in disability rights or independent living planning, services or advocacy. Lack of recognition makes it extremely difficult to receive any kind of accommodations. CILs can help by officially acknowledging FMS as a disability and proactively offering advocacy and services to those who are affected.

Where Can I Find More Information About FMS?

National Fibromyalgia Partnership, Inc. (NFP), 140 Zinn Way, Linden, VA 22642-5609. 866-725-4404. <http://www.fmpartnership.org>. NFP offers a wide array of services and activities to consumers and professionals.

Fibromyalgia Network, PO Box 31750, Tucson, AZ 85751, 800-853-2929. <http://www.fmnetnews.com>. This is the largest self-help organization for individuals with FMS, offering educational material related to research, treatment, coping strategies, and advocacy efforts. It also provide Web links to companies offering living aids. The quarterly newsletter is “Fibromyalgia Network.”

Fibromyalgia and Chronic Myofascial Pain; A Survival Manual (2nd Edition). Devin J. Starlanyl and Mary Ellen Copeland. New Harbinger Publications. June 30, 2001. This book discusses all aspects of both disorders, and also offers information on the latest medications, tips for bodywork, and suggestions for coping with family and work, getting support, and dealing with the healthcare system.

Fibromyalgia Personal Support Center Discussion Wall. This internet support site can provide contact with and information from persons living with fibromyalgia. www.fmpsc.org/wall/discussion.html

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