

PURPOSES OF THE NJCFSA

The New Jersey Chronic Fatigue Syndrome Association, Inc. (NJCFSA) is a registered 501(c)(3) nonprofit tax-exempt organization, whose purposes include supporting patients and their families, disseminating reliable information about the illness, facilitating communication between healthcare providers and patients and promoting research into the causes, methods of diagnosis, treatments, and cure of Chronic Fatigue Syndrome (CFS).

ABOUT CHRONIC FATIGUE SYNDROME

Chronic Fatigue Syndrome is a serious, complex and often disabling illness, which causes incapacitating fatigue and a wide array of immune, neurological, endocrine, cardiovascular and other symptoms. CFS symptoms are made worse by physical and mental activity and are not relieved by rest. A patient's ability to function is substantially lowered.

CFS is a global illness and in many parts of the world including the U.S., it is also known as Myalgic Encephalomyelitis (ME). Currently the acronyms ME/CFS and CFS/ME are being used worldwide. It is sometimes known as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS).

Over one million American men, women and children are estimated to have ME/CFS, but research shows that less than 20% of them have been diagnosed. ME/CFS affects all races, all socio-economic groups and all ages. In adults, four times as many women as men have ME/CFS, but the gender ratio is almost equal in children.

SYMPTOMS AND DIAGNOSIS OF ME/CFS

There is no specific diagnostic test for ME/CFS. The diagnosis depends upon the patient's symptoms meeting the criteria of one of several case definitions. The 1994 International Case Definition is the most commonly used¹. However, it excludes some patients with genuine ME/CFS who do not exactly fit the criteria. The newer Canadian Clinical Case Definition was produced to overcome this problem and it includes more symptoms commonly found in patients with ME/CFS². A pediatric case definition is available for diagnosing children and adolescents³.

Both case definitions include:

1. The new onset of unexplained, persistent or relapsing physical and mental fatigue that has lasted for at least six months and has substantially reduced activity levels; the fatigue is not the result of exertion and is not relieved by rest.
2. A medical history should be taken and a clinical examination and medical testing should be done to exclude other fatiguing illnesses; only after other illnesses have been ruled out can a diagnosis of ME/CFS be made.

The International Case Definition also requires the presence of four of the following eight symptoms: post-exertional malaise lasting more than 24 hours, non-refreshing sleep, difficulty in concentration or short term memory, muscle pain, painful joints without redness or swelling, a new type or increased severity of headaches, sore throats, tender lymph nodes in the neck or armpits.

The Canadian Clinical Case Definition also includes:

1. Malaise and worsening of symptoms after exertion; recovery is delayed for more than 24 hours.
2. Unrefreshing sleep, nighttime insomnia, and/or daytime hypersomnia (excessive sleep).
3. Widespread, migratory pain in muscles or joints (without swelling), or headache of a new type or increased severity.
4. At least two neuro-cognitive symptoms, including: confusion, impaired concentration, impaired short-term memory, disorientation, difficulty finding words and/or numbers, disturbed balance, hypersensitivity to noise, light or emotional overload.
5. At least one symptom from two of the following three subcategories:

a. Autonomic manifestations: facial pallor, neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), dizziness, palpitations, irritable bowel syndrome, urinary frequency.

b. Neuroendocrine manifestations: low body temperature, intolerance to heat and cold, feeling feverish, sweating, abnormal appetite or symptoms that worsen with stress.

c. Immune manifestations: tender lymph nodes, recurrent sore throats, recurrent flu-like symptoms, or a new sensitivity to food, medications or chemicals.

The pattern of symptoms differs in patients and symptoms may vary in severity from day to day or during the day.

PROGRESS AND TREATMENT OF ME/CFS

Most patients have a sudden onset of the illness with fever and flu-like symptoms, but sometimes the onset is gradual. After the initial onset, some patients improve slowly and are able to return to work, full or part time. Other patients live with relapses and remissions. However, some patients remain disabled and housebound. Less than 15% of patients recover within 10 years.

Although there is no cure for the illness as yet, medication can be useful in the relief of individual symptoms. Management is aimed at helping patients to pace themselves by adapting their lifestyle to live within their existing capabilities.

CAUSES OF ME/CFS

Numerous physiological differences between healthy and ME/CFS affected people have been found. Researchers are investigating factors such as genetics, a variety of infectious agents, environmental toxins, physical trauma and their complex interactions in producing the syndrome.

References: 1. Fukuda K, et al. *Annals of Int. Med.* 1994; 121:953-959. 2. Carruthers BM, et al. *J. Chronic Fatigue Syndrome* 2003; 11(1):7-115. 3. Jason LA, et al. *J. CFS* 2006;13 (2/3):1-28.

GOVERNMENT RESPONSE TO CFS

CFS (ME/CFS) is recognized by every U.S. Federal Health Agency as a serious illness. The Centers for Disease Control and Prevention (CDC) classifies CFS (ME/CFS) as a biomedical syndrome. The National Institutes of Health (NIH) and the CDC fund research and public education for ME/CFS.

The Social Security Administration instituted a policy (SSR-99-2P), which accepts medical diagnostic parameters for CFS. To qualify for disability benefits, the patient's physician must show that the patient has CFS and prove that the patient has both a medically determinable impairment and that they are unable to engage in any substantial employment.

The Department of Health and Human Services (DHHS) established the CFS Advisory Committee (CFSAC), comprised of representatives from the Federal Health Agencies and the medical and advocacy communities, to make recommendations to the DHHS concerning ME/CFS.