CFIDS as a Disability

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Under the Social Security Act "disability" is defined as the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment (or combination of impairments) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. This means that the impairment must prevent the individual from performing not only his or her past job but any other job in the national economy. The definitions of 'disability' under most long term disability policies are similar to Social Security's definition, however, some long term policies only require that the individual be unable to perform his or her own occupation for the first 24 months. In addition, some long term policies specifically limit benefits for CFS (and other impairments based upon self-reported symptoms) to 24 months. For any application for disability benefits under an employee long term disability policy, it is essential to review the policy language.

Both the Social Security Administration and most long term disability carriers recognize Chronic Fatigue Syndrome (CFS or CFIDS) as a disease and an impairment that can be disabling. Children, as well as adults, can be inflicted with disabling CFS which can entitle them to benefits under the Social Security Act. (most children do not qualify for long term benefits since these are only available through employment). CFS constitutes a medically determinable impairment when it is accompanied by certain medical signs or laboratory findings. Also, the level of severity of the CFS must reach a level that renders the individual unable to perform substantial gainful activity in order to be found disabled under the Social Security Act and under most long term policies.

Definition of CFS

The Social Security Administration, through its rulings and Program Operations Manual System ('POMS") defines CFS as "a systemic disorder consisting of a complex of symptoms that may vary in incidence, duration, and severity. It is characterized in part by prolonged fatigue that lasts 6 months or more and that results in substantial reduction in previous levels of occupational, educational, social, or personal activities." Social Security Ruling 99-2p; POMS DI24515.075. These documents recognize that CFS has been diagnosed in children, particularly adolescents, as well as in adults.

The hallmark of CFS is the presence of clinically evaluated, persistent or relapsing chronic fatigue that is of new or definite onset (i.e., has not been lifelong), cannot be explained by another physical or mental disorder, is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social, or personal activities. Additionally, the current CDC definition of CFS requires the concurrence of 4 or more of the following symptoms, all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have pre-dated the fatigue:

- Self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities;
- · Sore throat:
- Tender cervical or axillary lymph nodes;
- Muscle pain;
- Multi-joint pain without joint swelling or redness;
- Headaches of a new type, pattern, or severity;
- Unrefreshing sleep; and
- Postexertional malaise lasting more than 24 hours.

Social Security Ruling 99-2p; POMS DI24515.075

Social Security also recognizes that "an individual with CFS can also exhibit a wide range of other manifestations, such as muscle weakness, swollen underarm (axillary) glands, sleep disturbances, visual difficulties (trouble focusing or severe photosensitivity), orthostatic intolerance (e.g., lightheadedness or increased fatigue with prolonged standing), other neurocognitive problems (e.g., difficulty comprehending and processing information), fainting, dizziness, and mental problems (e.g., depression, irritability, anxiety)." Social Security Ruling 99-2p; POMS DI24515.075.

Examples of Laboratory Findings that Establish the Existence of a medically determinable impairment

For purposes of Social Security disability evaluation, one or more of the following medical signs clinically documented over a period of at least 6 consecutive months establishes the existence of a medically determinable impairment for individuals with CFS:

^{1.} There is considerable overlap of symptoms between CFS and fibromyalgia, but individuals with CFS who have tender points have a medically determinable impairment.

- Palpably swollen or tender lymph nodes on physical examination;
- Nonexudative pharyngitis;
- Persistent, reproducible muscle tenderness on repeated examinations, including the presence of positive tender points; or,
- Any other medical signs that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record.

Social Security Ruling 99-2p; POMS DI24515.075.

Examples of Laboratory Findings that Establish the Existence of a medically determinable impairment

At this time, there are no specific laboratory findings that are widely accepted as being associated with CFS. However, the absence of a definitive test does not preclude reliance upon certain laboratory findings to establish the existence of a medically determinable impairment in persons with CFS. Therefore, the following laboratory findings establish the existence of a medically determinable impairment in individuals with CFS: ²

- An elevated antibody titer to Epstein-Barr virus (EBV) capsid antigen equal to or greater than 1:5120, or early antigen equal to or greater than 1:640:
- An abnormal magnetic resonance imaging (MRI) brain scan;
- Neurally mediated hypotension as shown by tilt table testing or another clinically accepted form of testing; or,
- Any other laboratory findings that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record; for example, an abnormal exercise stress test or abnormal sleep studies, appropriately evaluated and consistent with the other evidence in the case record.

Mental Findings that Establish the Existence of a medically determinable impairment

Some individuals with CFS report ongoing problems with

- short-term memory,
- information processing,
- visual-spatial difficulties,
- comprehension,
- concentration,
- speech,
- word-finding,
- calculation, and
- •other symptoms suggesting persistent neurocognitive impairment.

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^{2.} It should be noted that standard laboratory test results in the normal range are characteristic for many individuals with CFS.

When ongoing deficits in the above areas have been documented by mental status examination or psychological testing, such findings constitute medical signs or (in the case of psychological testing) laboratory findings that establish the presence of a medically determinable impairment.

Individuals with CFS may also exhibit medical signs, such as anxiety or depression, indicative of the existence of a mental disorder. When such medical signs are present and appropriately documented, the existence of a medically determinable impairment is established.

It is important to remember that the above medical signs, laboratory signs, and mental findings only establish the existence of CFS as a 'medically determinable impairment' which is a requirement of the Social Security Administration before it determines the severity of your symptoms. Those medical signs, alone, do not establish CFS as a disabling impairment.

Proving Disability

CFS does not differ from other impairments, physical or mental, when it comes to whether the individual is disabled, that is, unable to work. Usually, being unable to work mean being unable to be employed on a regular and continuous basis, 8 hours a day, 5 days a week in a competitive work environment. A standard work day requires work for 2 hour periods of time with 15 minute breaks in the morning and afternoon and a one hour lunch break. If an individual cannot consistently maintain that type of schedule, in most cases, a finding of 'disabled' will follow. However, for individuals who have obtained sufficient skills from past work which would allow them to have employment that varies from that traditional work schedule, that individual might not be found disabled, assuming he or she could perform SGA within a schedule that they could maintain.

Also, in some cases, an individual could be found 'not disabled' even if that individual was restricted to part time work, if they had transferable skills to part time work that produced SGA. At the present time, SGA is \$900.00 gross earnings per month, so if the individual is capable of working part time and earning \$900.00 per month they will be found to be 'not disabled'. This is an important consideration in CFS cases since, in my experience, many individuals who suffer from CFS have a skilled background of work experience.

In proving disability, under either the Social Security Act or a long term policy, it is essential to have the support of your primary care physician. Although this applies to application for disability for any impairment, it is most important when it comes to CFS. It is also essential that your primary care physician both understand and recognize CFS as a disease that can be debilitating. Many physicians and other health care

providers still do not "believe in" CFS. If your physician or health care provider is one of those, you should seek a provider that does understand your impairment, both for your own benefit and for support of your disability application.

A treating physician, whether it is a primary care physician or a specialist who treats you, is given deference by the Social Security Administration. If their opinions are well-supported by medically acceptable clinical and laboratory diagnostic techniques and are not inconsistent with the other substantial evidence in your case record, Social Security will give that treating physician's opinion 'controlling weight'. Long term administrators do not have to afford a treating physician's opinion extra weight, but they are very important, and often essential, as support for your claim.

Since your treating physician's opinions are essential to support an application for disability based upon CFS and because of the very nature of CFS (not being demonstrated on objective testing), it is essential that you continually inform your treating physician of all of the signs and symptoms that you are experiencing as well as all of the restrictions and limitations that you have. Both Social Security and a long term insurance company will obtain all of your treating physician's office notes for your care and they will examine these notes in their evaluation process. Therefore, you should make sure that your provider has full, complete, and up to date information about your medical condition, your symptoms and restrictions and limitations.

When you discuss your condition with your doctor you should been specific about your restrictions and limitations. For instance, instead of telling your doctor that you get tired and fatigued, tell him/her that after a specific number of hours you get tired to the point that you have to lie down and rest for a specific period of time. Also, if your focus or concentration starts fading after a specific period of time, mention that to your doctor. You should prepare when you see your doctor and give him/her a full picture of your condition and how it has affected your ability to perform tasks since your last visit. The more your doctor knows and records in the office notes, the easier it is to show why you are unable to work.