

**HOW TO APPLY FOR  
SOCIAL SECURITY DISABILITY BENEFITS  
IF YOU HAVE  
CHRONIC FATIGUE SYNDROME  
(CFS/CFIDS)  
MYALGIC ENCEPHALOPATHY (ME)  
and  
FIBROMYALGIA (FM)**

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## **DISCLAIMER**

The Massachusetts CFIDS/ME & FM Association serves as a clearinghouse for information about Chronic Fatigue Immune Dysfunction Syndrome/Chronic Fatigue Syndrome (CFIDS/CFS), Myalgic Encephalopathy (ME) and Fibromyalgia Syndrome (also known as Fibrositis).

This book is intended to give people ideas as to what is involved in qualifying for some programs which provide disability or other benefits. The book is not intended to cover all programs and is not intended to be a substitute for the advice of a competent attorney. This book reflects an accumulation of opinions and experiences of different individuals and advocates and nothing more. For legal advice it is imperative to consult with an attorney or qualified legal advocate of your own choosing. Further, the law is fluid and what applies in Massachusetts at a particular time may not apply elsewhere and visa-versa. Moreover, what is valid today in this booklet when it goes to press may not be valid after it is published. The Massachusetts CFIDS/ME & FM Association, Kenneth Casanova, and any and all persons who participated in authoring, contributing to, or producing this booklet assume no responsibility for any use of this booklet by its readers or for any results or consequences of such usage or further, for any other activity which occurs from the reading of the booklet or the application of its content.

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## HOW TO USE THIS BOOK

The book is long because there are so many aspects of the Social Security Disability process, and each requires detailed discussion in order that you will be well-informed so that you can make the best decisions possible.

Fortunately, I hope, this book is well-organized. The book is not meant to be read through entirely. You should use the Table of Contents to find what you need to know according to what step of the Social Security Disability process you are in.

If you want to know if you are potentially eligible to apply, start by reading the Introduction. If you decide to apply, then you must read the main body of the booklet after the Introduction, as well as Appendix II and Appendix IV. If you already have an up-to-date and well-documented CFS diagnosis, you may want to skip the section on “Obtaining a CFS Diagnosis.”

It is very important that everyone read, no matter what stage you’re involved in, the section on the **1999 CFS Ruling**, because it’s so important.

If your doctor needs help in knowing how to diagnose CFIDS or FM, give him/ her Appendix I.

If you reached the Administrative Law Judge hearing stage, turn to Appendix III. If you’re getting reviewed, turn to Appendix VI.

If you are a lawyer and are looking for positive legal precedents for winning CFS or FM Disability claims, see Appendix V.

If you are applying for disability through your employer, read Appendix VII and Appendix IV. You should also look at the Resource Section.

You get the idea: **Navigate using the Table of Contents.**

Just to let you know. This booklet has been an ongoing project since the early 1990s. It contains the advice of lawyers, disability specialists, and the experience of many disability claimants. I can say, from the reports of patients with CFIDS, that it has helped many. I hope it helps you.

Ken Casanova

## **HOW TO APPLY FOR SOCIAL SECURITY BENEFITS IF YOU HAVE CHRONIC FATIGUE SYNDROME (CFS/CFIDS)**

### **I. The Application Process**

People with CFS who are applying for Social Security benefits should know that the application process could sometimes be difficult and frustrating. However, despite the difficulties of applying, if you are willing to take a “stick-to-it” attitude and not give up, *chances are quite good that you will be awarded benefits.*

If you are prepared for some difficulties and frustrations at the beginning, it will be easier for you to cope; setbacks can be recognized as temporary and can act as an incentive to do what’s necessary at the next stage. You should keep in mind that these setbacks do not at all prevent a favorable, final outcome.

At the outset, you need both to be psychologically prepared for difficulties and to have hope.

*If you have a reasonably serious case of CFS and are unable to do even light, sedentary work on any scheduled, ongoing basis, and this situation is expected to be continuous for at least a year, then chances can be quite good that you will ultimately win benefits.*

You must stick with the process and provide Social Security with all necessary information, including seeing Social Security’s physicians or specialists (unless you can persuade Social Security that such appointments are unnecessary or a hardship - but if Social Security insists, such appointments should be kept).

*It is also crucial to file the necessary appeals within the required time limits.*

#### **Very Important**

**Very often people are rejected at both the initial application stage and at the reconsideration stage without a complete and fair review of their cases. Such rejections at the first two stages are common and to be fully expected - so the applicant should not be devastated or give up if s/he receives such a rejection.**

The fact is that applicants may receive a fair evaluation of their case only during the third stage - at the hearing before the administrative law judge. Most often, it is only at this hearing stage that CFS applicants are finally awarded benefits. So an applicant must continue with the process until s/he reaches the third stage - this is when the person’s chances are best.

However, the applicant must not think s/he doesn't have to make *a full effort to provide Social Security with all necessary information at the first and second stages*. It is absolutely necessary to make an all-out effort to comprehensively document your illness at the first two stages.

The applicant should also realize that although s/he may have to wait many months for a favorable decision by the administrative law judge, the wait is not in vain since a favorable decision means that benefits will be awarded retroactively.

## **II. When to Obtain a Lawyer**

During the initial application process, if you have questions or concerns about either how to apply or how to fill out the application, you should obtain the advice of an Advocate (not necessarily a lawyer) familiar with the disability process. You can call the Mass. CFIDS/ME & FM Disability Committee, or your local legal assistance office. During the application stage, you do not necessarily need legal representation; however, getting sound advice early on may help you avoid mistakes that could later be detrimental to your claim.

If you are rejected at the first two stages, you should obtain a lawyer or legal representative to present your case before the administrative law judge. The lawyer should be a specialist in and have had experience with representing disability cases.

If you are low income, you can obtain a lawyer through the local legal assistance office. Otherwise, the lawyer can be hired on a contingency basis, which means the lawyer only receives compensation (a percentage of the retroactive disability benefit) if you win your case. If you are not low income, the Mass. CFIDS/ME & FM Disability Committee can refer you to a lawyer who will handle your case on a contingency basis. The contingency fee is limited to a maximum of 25% of the retroactive award, and cannot exceed \$4,000. The final attorney's fee is determined by Social Security. You should always obtain a *written* fee agreement if you have a private attorney.

If you are receiving benefits from an employer-related disability policy, the insurance company may be willing to pay the cost of an attorney.

Counselors are encouraged to obtain the names of any attorneys that applicants endorse as having helped them. The Mass. CFIDS/ME & FM Disability Committee can then develop a lawyer referral list to assist Mass. CFIDS/ME & FM Association members. If you need help with a lawyer referral, the Mass. CFIDS/ME & FM Disability Committee may be able to assist you. Call Ken at: (617)522-5835.

## **III. When To Apply for Disability**

To be eligible for Disability (SSDI or SSI), a person with CFS must no longer be able to do even light, sedentary, part-time work, on any continuing basis, and his/her inability to work must be expected to last (or has lasted) for at least one year.

This means, first (with rare exceptions), that a person should not be working, even part-time, when s/he applies.

Second, you should apply as soon as possible after you become disabled and unable to work. To be found eligible, however, Social Security must determine that your inability to work is expected to last for at least a year. If you apply within a short time after leaving work, ask your doctor to include in his letter to Social Security that you will not be able to return to work for at least a year. Or state that your ability to return to work is not expected to change (or will be unpredictable) for at least a year.

Of course people with CFS have often been out of work many months before they apply for disability. If you already have been out of work at the time you apply, your period of unemployment should count toward filling the one-year requirement.

To properly pursue your application, you and your doctors must document as fully as possible your diagnosis of CFS. Proper diagnosis of CFS, according to the Centers for Disease Control guidelines, requires that the symptom complex must have lasted for at least six months. Therefore, until you have been sick for close to six months, it will be difficult for your doctor to confirm a CFS diagnosis. However, this six-month diagnostic period is usually not a problem in applying for disability, since many patients have been sick for at least six months before they apply for disability. (This diagnosis requirement has no relation to your employment status - in other words, you can count six months of illness for diagnostic purposes while you were still working, before you apply for disability.)

The basic rule is that you should apply as soon as you are no longer able to work, regardless of certainty of diagnosis.

If you are no longer able to work, Social Security must accept your application. There are times when someone at Social Security may be unfamiliar with CFS, or for some other reason try to discourage you from applying. If this happens, you should insist on your right to file an application. If Social Security does not let you file, you should immediately contact: *Mass. CFIDS/ME & FM Disability Committee* (617) 522-5835.

#### **IV. Your Doctors' Letters to Social Security**

In order to, successfully, medically document your disability to Social Security through the various stages of the application and appeals process, **it is necessary to develop and maintain a constructive and ongoing relationship with a physician who can medically verify your disability.** After you have been approved for disability, you should continue to maintain an ongoing physician relationship since Social Security will require you to medically document your disability during periodic reviews, which occur at various intervals. Maintaining an ongoing physician relationship is very important in obtaining and maintaining your Social Security Disability.

Normally, in the application, Social Security will ask you to list all the doctors who have treated you for your disabling illness(es). Social Security should send the paperwork to your doctors to enable them to document your disability. However, in addition to these submissions, you should ask at least one of your doctors (often your primary care physician) to write a comprehensive medical report

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(letter) documenting, in detail, how your diagnosis was made. All your medical signs, symptoms, and lab tests should be detailed. Secondly, your doctor should document the physical and cognitive limitations that prevent you from working. **The new Social Security Ruling on CFS (1999, see below)** specifically lists medical signs and lab tests which, when possible, should be documented. When the listed signs and lab tests cannot be provided, make sure to include all the signs, symptoms, and lab tests consistent with CFS.

The Ruling requires doctors to back-up their documentation of medical signs/lab tests/functional limitations from a longitudinal clinical record covering the past 12 months. To do this the physician can append to the medical report **copies of his notes from each office visit as well as lab test reports.**

Your doctors' letters to Social Security, along with other medical documentation, are important in obtaining a favorable decision.

Letters from your doctors should seek to accomplish the following *two objectives*:

- 1) The letters should fully establish and document your CFS diagnosis.
- 2) These letters should establish that, as a result of your illness, you can no longer do any work, even light, sedentary, part-time work on any continuing, scheduled basis. Your doctor should state that this inability to work is expected to last at least 12 months.

Generally, 2 types of doctor's letters are submitted:

- 1) Letters which fully establish and document both the CFS diagnosis, and the patient's inability to work. These letters will be from the primary care physician or from a specialist who is in a position to provide the necessary information. Included with such letters should be the results of tests taken by the doctor which provide support for the CFS diagnosis. These letters should also document specific treatments undertaken (including use of medications) as well as the results of such treatments.
- 2) The second type of letter - which acts to supplement the comprehensive letter described above - documents a particular element or aspect of the illness. This type of submission would include the results and evaluation of neuropsychological testing or the results (including lab tests) of neurological, hematological, immunological, or psychiatric examinations which support your CFS diagnosis. Naturally, a specialist would write this type of letter. Where possible, the provider should explain how the findings would prevent you from working.

This category of supplementary letter would also include letters documenting your inability to work (or more technically, your "residual functional capacity"). Such letters might be written by a rehabilitation specialist, an occupational therapist, physical therapist, etc. Letters documenting your physical incapacity to work can also be submitted by people who are in a good position to observe your limitations and difficulties in daily life, including family, friends, etc. People writing these letters should give specific examples (from their actual observations) of your difficulties in performing various household tasks, in meeting your own personal care needs, or in performing your other family responsibilities. Friends might write of their observations of the decline of your health, your having to leave your job, or your having to give up your social life or community work. Finally, letters from people with whom you have a more professional relationship, such as teachers, clergy, former

employers, etc. can be very helpful. Again, these letters should attest to the disabling changes and limitations caused by your illness.

You should ask your doctor(s) and anyone else sending letters or medical records to Social Security on your behalf to also send you a copy of what has been submitted. By doing so, you will know exactly what documents have been sent and when; you will also know what information has been included in the documents (in case you need to ask your provider to send Social Security additional information). Finally, having copies of the documents will be very helpful if you need to appeal.

For more information and suggestions on how to work with your doctor(s) in preparing and submitting reports to Social Security, see the Appendix.

## **Letters from your Primary Care Physician**

We will deal first with the primary doctors' letters, which should fully establish and document your CFS diagnosis and your inability to do any scheduled work ("residual functional capacity"). You should obtain this type of letter from at least one physician *who recognizes and understands CFS* and who is willing to write such a comprehensive letter. By reading these instructions you will be able to explain to your doctor what his/her letter should contain to best support your application. If you can obtain this type of comprehensive letter from more than one doctor, you should definitely do so.

If you would like information that would help you better communicate with your doctor and establish a more productive patient-physician relationship, Mass. CFIDS/ME & FM can provide you with an information packet. Call or write to obtain this information.

*Important information for individuals with fibromyalgia applying for Social Security benefits:*

Apparently, individuals with a diagnosis of fibromyalgia have greater difficulty than those with chronic fatigue syndrome in obtaining approval of their claim for social security benefits. Many medical authorities are of the opinion that CFS and fibromyalgia are either the same illness or are very closely related illnesses. Therefore, when applying for disability benefits, a person with a diagnosis of fibromyalgia would be advised to determine whether he or she could also obtain a diagnosis of CFS. Very often a diagnosis of fibromyalgia is obtained after consulting with a rheumatologist. Following such a diagnosis, many individuals have found that they can also obtain a CFS diagnosis by consulting a doctor familiar with CFS such as an Infectious Disease Specialist.

## **Obtaining a CFS Diagnosis**

Note: Patients who already have obtained a full diagnosis by a physician familiar with the proper diagnosis of CFS may want to skip onto page 999, since this section explains the comprehensive method of diagnosis according to the 1994 CFS Centers for Disease Control diagnostic criteria recognized by Social Security. However, for those patients still needing a diagnosis, this section will fully inform you as to the recognized method. All CFS patients applying for Social Security should at least be familiar with the diagnostic criteria.

To successfully apply for Social Security Disability benefits, an applicant should obtain a medically



recognized diagnosis of his or her disabling illness or condition. In December, 1994, the U.S. Centers for Disease Control issued new guidelines for the medical diagnosis of Chronic Fatigue Syndrome. The new diagnostic criteria are contained in an article, "The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study," published in the *Annals of Internal Medicine*, December, 1994 (see Appendix 1 for entire article.) The new diagnostic criteria are intended to replace the former diagnostic criteria published in 1988.

The new criteria were designed to provide a formal, internationally-recognized method for the diagnosis of CFS. Over time, the new diagnostic criteria will gain weight among doctors, insurance companies and government agencies as a favored standard for evaluating and documenting a CFS diagnosis. However, the guidelines were specifically developed for research purposes; in order to maintain research clarity, a small minority of CFS cases will be excluded under the new definition. However, the new guidelines themselves state, "However, none of the components including the revised case definition can be considered definitive." In other words, a doctor who is well informed about CFS can still make a CFS diagnosis even if the new guidelines exclude such a diagnosis. (Necessary advice on gaining a diagnosis for a CFS case excluded by the new guidelines is provided below.) Generally, however, under the new guidelines, many cases of CFS will be more easily diagnosed than would have been possible under the 1988 guidelines. (Note: please see Appendix 1 for a note on the new 2003 Canadian CFS/ME Diagnostic Criteria.)

Under the new guidelines, the diagnostic process for CFS is divided into three primary phases:

1. *The Clinical Evaluation Phase*, which consists of a medical and psychological history and evaluation, and laboratory screening tests.
2. *The Exclusion/Inclusion Phase* is divided into two parts: an Exclusion Phase and an *Inclusion Phase*. Based on the finding of certain illnesses and conditions other than CFS during the Clinical Evaluation Phase, an additional diagnosis of CFS may at this point be excluded. Or, alternatively, a subsequent diagnosis of CFS may still be permitted (despite the finding of a different illness or condition).
3. *The CFS Diagnosis Phase* is the actual diagnosis of CFS based on a specific symptom profile. The guidelines also contain the new diagnosis of idiopathic chronic fatigue, which is chronic fatigue which fails to meet the criteria for the Chronic Fatigue Syndrome and remains unexplained despite the comprehensive clinical evaluation prescribed by the guidelines.

This next section consists of a detailed summary and explanation of the procedure for obtaining and documenting a CFS diagnosis based on the new CDC guidelines.

**Clinical Evaluation Phase:** An individual suffering from chronic fatigue (defined as: self-reported persistent or relapsing fatigue, lasting six or more consecutive months) is required to undergo the following clinical evaluation. This is to identify underlying or contributing conditions that require treatment and that may either exclude or permit a further diagnosis of CFS. The steps in clinical evaluation are as follows:

1. A thorough history that covers medical and psycho-social circumstances at the onset of

fatigue, depression or other psychiatric disorders; episodes of medically unexplained symptoms; alcohol or other substance abuse; and current use of prescription and over-the-counter medications and food supplements.

2. A mental status examination to identify abnormalities in mood, intellectual function, memory, and personality. Particular attention should be directed toward current symptoms of depression or anxiety, self-destructive thoughts, and observable signs such as psychomotor retardation. Evidence of a psychiatric or neurologic disorder requires that an appropriate psychiatric, psychological, or neurologic evaluation be done.

In these two initial steps of evaluation, in addition to a medical evaluation, there is a clear emphasis on evaluating possible psychiatric conditions. This emphasis on psychiatric evaluation may create problems for some individuals with CFS in obtaining a diagnosis and in applying for Social Security. By understanding the potential pitfalls of psychiatric evaluation, an informed individual with CFS can avoid and minimize the effect of unnecessary and misguided psychiatric evaluation in his/her effort to obtain a diagnosis and social security benefits. The introduction of a finding of depression into the CFS diagnostic process and in an application for Social Security can complicate or may even jeopardize obtaining a diagnosis and gaining disability benefits.

Item 1 (just quoted) requests an evaluation of any depression, both preceding and following the onset of the fatiguing illness. It is critical for the diagnosis of CFS and for the Social Security application that the patient and the physician clearly distinguish between a primary and secondary depression. A primary depression, either currently or in the past, could exclude or make more difficult a diagnosis of CFS; while a finding of secondary depression can be very consistent with a CFS diagnosis. Secondary depression often occurs as a reaction to a chronic physical illness as an individual's response to a lack of physical improvement and the limitations imposed by the illness. Also any evaluation of a history of depression prior to the illness' onset should distinguish between major severe chronic depression, and infrequent episodes of minor depression. For a full explanation of the importance of evaluating depression for both diagnostic purposes and in applying for Social Security, see other pages in this booklet, including Appendix IV.

Item 2 (quoted above) in this evaluation phase requires "a mental status examination" for all patients to be given by the diagnosing physician. The term, "mental status examination", does not refer to any standardized or formal test or procedure of evaluation; instead, the term refers to a fairly informal and basic assessment of the presence of any disorders or symptoms listed in item 2; certainly what constitutes a "mental status examination" will vary among examining physicians. Item 2 indicates that if evidence of a psychiatric or neurological disorder is found, then a further psychiatric, psychological or neurological evaluation would be required.

Here there is a potential pitfall for a genuine CFS sufferer. Many CFS patients do not suffer from significant depression or other emotional disorder because of their illness; however, they do suffer the expected emotional trouble and frustrations that result from a chronic physical illness. Since these individuals do not suffer from a "psychiatric disorder," they should discuss with their physician any requested psychiatric evaluation. Such evaluations occasionally result in a psychiatric misdiagnosis which then can complicate the diagnostic process as well as the individual's Social Security application. Even an individual who suffers from significant secondary depression due to the CFS should discuss with his or her examining physician whether the level of depression warrants a further

psychiatric referral.

If such a referral is made the patient should explain to the specialist that the depression is a result of their physical illness. Also during this mental status examination it is important for the patient and the physicians to distinguish cognitive dysfunction (memory and thinking problems) and neurological problems caused by the CFS from psychologically caused conditions. For more information on cognitive dysfunction caused by CFS, as opposed to psychological disorder, see other sections of this booklet. Referrals to specialists who understand CFS for the assessment of cognitive dysfunction and neurological disorder can certainly be helpful in a diagnostic process and in the Social Security application process.

The next items in the evaluation phase provide for:

3. A thorough physical examination.
4. A minimum battery of laboratory screening tests including complete blood count with leukocyte differential; erythrocyte sedimentation rate; serum levels of alanine aminotransferase, total protein, albumin, globulin, alkaline phosphatase, calcium, phosphorus, glucose, blood urea nitrogen, electrolytes, and creatinine; determination of thyroid-stimulating hormone; and urinalysis.

Routinely doing other screening tests for all patients has no known value (20,30). However, further tests may be indicated on an individual basis to confirm or exclude another diagnosis, such as multiple sclerosis. In these cases, additional tests or procedures should be done according to accepted clinical standards.

The next two paragraphs (from the CDC definition) go on to state that, presently, except for the purpose of specialized research there are no further recommended tests for the diagnosis of Chronic Fatigue Syndrome:

The use of tests to diagnose the chronic fatigue syndrome (rather than to exclude other diagnostic possibilities) should be done only in the setting of protocol-based research. The fact that such tests are investigational and do not aid in diagnosis or management should be explained to the patient.

In clinical practice, no additional tests, including laboratory tests and neuroimaging studies, can be recommended for the specific purpose of diagnosing the chronic fatigue syndrome. Tests should be directed toward confirming or excluding other etiologic possibilities. Examples of specific tests that do not confirm or exclude the diagnosis of the chronic fatigue syndrome include: serologic tests for Epstein-Barr virus, retroviruses, human herpes-virus 6, enteroviruses, and *Candida albicans*; tests of immunologic function, including cell population and function studies; and imaging studies, including magnetic resonance imaging scans and radionuclide scans (such as single-photon emission computed tomography and positron emission tomography) of the head.

Here the CDC clearly recommends that for the general clinical diagnosis and management of CFS,

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physicians and patients should not seek more specialized testing (except to exclude other possible illnesses). Despite these recommendations, Social Security, recently, has placed some emphasis on the use of "objective laboratory testing" in order to confirm a CFS diagnosis. Therefore, any more specialized testing available to a CFS applicant which demonstrates abnormalities consistent with a CFS diagnosis would be helpful in obtaining Social Security. However, such specialized testing, as the guidelines make clear, is not available to most CFS patients and is not required to obtain Social Security benefits.

***The second phase of the diagnostic process*** may be called the *Exclusion/inclusion Phase*. In this phase, findings of the *Evaluation Phase* may either exclude a diagnosis of CFS or allow for a diagnosis of CFS. The first part of this phase is the *Exclusion Phase*. Under these guidelines the finding of an exclusionary illness or condition prevents a diagnosis of CFS. However, the finding of an exclusionary condition does not necessarily mean that an individual does not have CFS. The guidelines make clear that they were designed for research purposes and in order to maintain research clarity, a diagnosis of CFS has been excluded when other illnesses or conditions are present. The guidelines themselves state:

...none of the components, including the revised case definition of the Chronic Fatigue Syndrome, can be considered definitive.

Despite an excluding condition, a person with CFS may still obtain a diagnosis from a doctor who is well-informed about CFS. Such an individual can and should apply for Social Security benefits if he or she is disabled. The guidelines proceed as follows:

The following conditions exclude a patient from the diagnosis of unexplained chronic fatigue (which includes Chronic Fatigue Syndrome):

1. Any active medical condition that may explain the presence of chronic fatigue (31), such as untreated hypothyroidism, sleep apnea, and narcolepsy, and iatrogenic conditions such as side effects of medication.
  
2. Any previously diagnosed medical condition whose resolution has not been documented beyond reasonable clinical doubt and whose continued activity may explain the chronic fatiguing illness. Such conditions may include previously treated malignancies and unresolved cases of hepatitis B or C virus infection.

Note: Despite the guidelines, it is possible that an individual with another previously diagnosed illness which causes fatigue could also have Chronic Fatigue Syndrome.

3. Any past or current diagnosis of a major depressive disorder with psychotic or melancholic features; bipolar affective disorders; schizophrenia of any subtype; delusional disorders of any subtype; dementia of any subtype; anorexia nervosa; or bulimia nervosa.

Here the guidelines state that any current or previous major mental illness or bulimia or anorexia nervosa disqualifies an individual from receiving a diagnosis of CFS. Again, despite the guidelines,

an individual with one of these conditions, either in the past or the present, could suffer from CFS, receive a diagnosis for CFS, and receive Social Security on the basis of a CFS disability. For instance, an individual could develop CFS even though he or she had recovered from a major depression ten years previously. Again, individuals who have recovered from anorexia nervosa or bulimia nervosa could develop CFS years later. The guidelines clearly recognize these possibilities:

We distinguish between psychiatric conditions for pragmatic reasons. It is difficult to interpret symptoms typical of the Chronic Fatigue Syndrome in the setting of illnesses such as major psychotic depression or schizophrenia. More importantly, care of these persons should focus on their chronic psychiatric disorder.

Again individuals with these exclusionary conditions who also have Chronic Fatigue Syndrome should seek diagnosis from a doctor experienced in the diagnosis of Chronic Fatigue Syndrome and may apply for disability benefits on the basis of Chronic Fatigue Syndrome once a diagnosis has been made. Also it should be noted (see below) that other psychiatric conditions do not exclude a diagnosis of CFS under these guidelines.

4. Alcohol or other substance abuse within 2 years before the onset of the chronic fatigue and at any time afterward.

Again it is quite possible for a person who two years previously suffered from substance abuse to develop CFS and to be diagnosed accordingly.

5. Severe obesity (32, 33) as defined by a body mass index [body mass index = weight in kilograms / (height in meters)<sup>2</sup>] equal to or greater than 45.

Any unexplained physical examination finding or laboratory or imaging test abnormality that strongly suggests the presence of an exclusionary condition must be resolved before further classification.

Note: Again despite the guidelines the possibility exists, as discussed above, that an individual with severe obesity could also suffer from CFS.

The second part of this phase is the ***Inclusion Phase***. That is, the finding of conditions that do not exclude an additional diagnosis of CFS.

1. Any condition defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, including fibromyalgia, anxiety disorders, somatoform disorders, nonpsychotic or nonmelancholic depression, neurasthenia, and multiple chemical sensitivity disorder.

This step obviously allows for diagnoses of Fibromyalgia/CFS and multiple chemical sensitivity disorder/CFS. This step also allows for a CFS diagnosis even in the presence of the listed psychiatric conditions including non-psychotic depressions and anxiety disorders. This portion of the guidelines is a major improvement over the 1988 guidelines since it clearly states both to physicians and Social Security that an entire group of psychiatric conditions do not and must not necessarily exclude a diagnosis of CFS. Under these new guidelines neither a psychiatrist nor Social Security can summarily

dismiss a diagnosis of CFS to an individual with one of these psychiatric disorders. The finding of the following illnesses or conditions do not exclude a diagnosis of CFS:

2. Any condition under specific treatment sufficient to alleviate all symptoms related to that condition and for which the adequacy of treatment has been documented. Such conditions include hypothyroidism for which the adequacy of replacement hormone has been verified by normal thyroid-stimulating hormone levels, or asthma in which the adequacy of treatment has been determined by pulmonary function and other testing.
3. Any condition, such as Lyme disease or syphilis, that was treated with definitive therapy before development of chronic symptomatic sequelae.
4. Any isolated and unexplained physical examination finding or laboratory or imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition. Such conditions include an elevated antinuclear antibody titer that is inadequate to strongly support a diagnosis of a discrete connective tissue disorder without other laboratory or clinical evidence.

***The final CFS diagnostic phase*** of the CFS diagnostic process provides guidelines for the actual diagnosis of Chronic Fatigue Syndrome. An individual's chronic fatigue will be diagnosed according to the following CFS guidelines unless his or her chronic fatigue has been already "explained" through an exclusionary condition. The guidelines for CFS diagnosis are as follows:

A case of the chronic fatigue syndrome is defined by the presence of the following:

- 1) clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); 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; and
- 2) the concurrent occurrence of **four 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 predated 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 axially 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.

These guidelines complete the diagnosis of Chronic Fatigue Syndrome. If, however, chronic fatigue is not explained through a diagnosis of CFS or a previously explained (excluded) condition, a final diagnosis of idiopathic chronic fatigue may be reached.

A case of Idiopathic Chronic Fatigue is defined as clinically evaluated, unexplained chronic fatigue that fails to meet criteria for the Chronic Fatigue Syndrome. The reasons for failing to meet the criteria should be specified.

For instance (interpreting under these guidelines), an individual who had fully recovered from a major psychotic depression twenty years previously and who now develops disabling chronic fatigue and who under these guidelines is not eligible for a CFS diagnosis might well receive a diagnosis of idiopathic chronic fatigue. The question arises whether an individual who is applying for Social Security and who actually has CFS but is excluded under the new Criteria should apply under the diagnosis of idiopathic chronic fatigue or instead, despite the guidelines, should attempt to obtain a CFS diagnosis from a qualified physician. The answer is, if at all possible, for the disability application to be made under a CFS diagnosis since CFS is a formally recognized diagnosis under Social Security regulations. (**See 1999 CFS Ruling below.**) Idiopathic chronic fatigue is not such a formally recognized or listed diagnosis. Generally, a disabling CFS diagnosis would be more easily approved by Social Security than a disabling diagnosis of idiopathic chronic fatigue.

A final note on the new diagnostic criteria: The new criteria represent a major improvement over the 1988 criteria except in the case of a number of exclusions (discussed above) - this portion of the guidelines represents a partial set-back. Despite the fact that the guidelines should not be considered the final word on diagnosis (in the case of the exclusions discussed above), the limitations of the guidelines may not be understood by many doctors, insurance companies and some individuals and agencies administering disability programs. The new guidelines to some degree will gain influence as the primary and authoritative method for obtaining a diagnosis. Certainly the new guidelines will gain some influence with Social Security; however, individuals who have CFS but are excluded under the new guidelines will still likely be accepted by social security disability as long as their doctors provide sufficient medical documentation to confirm a CFS diagnosis and a resulting disability. In such circumstances the diagnostic method would be to evaluate according to the new criteria but not to eliminate CFS on the basis of the pertinent exclusion. The CFS would then be diagnosed on the basis of the symptom profile. Especially important in this type of diagnosis would be the documentation of history, treatments and the extent of resolution of any previous or current illness or condition that qualifies as exclusionary. Documentation of lab and other testing showing consistency with CFS and inconsistency with the exclusionary illness would be especially important. For example, in the case of a patient with CFS who recovered twenty years previously from a major psychotic depression, the physician would perform all the steps according to the criteria except for eliminating CFS on the basis of the former depression. The physician would then document the history, treatment and resolution of the former depression. Symptoms and lab and other testing results showing abnormalities consistent with CFS and inconsistent with psychotic depression would be emphasized.

Patients with CFS, who also have new exclusionary conditions, should also find the following list of symptoms and list of tests helpful in working with their physicians to document their CFS: "Some tests to be conducted to help determine objectivity of CFS/CFIDS and/or other disabling symptoms" and "Checklist of CFIDS symptoms" (for these lists see Appendix II.)

## **Documenting the CFS Diagnosis to Social Security**

On April 30, 1999, the Social Security Administration issued a critical new Ruling: "**Social Security Administration Ruling, SSR 99-2p.; Titles II and XVI: Evaluating Cases Involving Chronic Fatigue Syndrome (CFS).**" This Ruling explains, in detail, the specific documentation necessary to

successfully establish a Social Security claim for CFS. The Ruling lists the specific medical signs, symptoms, and laboratory tests to establish a CFS diagnosis.

Important: In addition to the listed medical signs and laboratory tests, the Ruling clearly states that other signs, symptoms, and laboratory tests **not listed** may be used to document a CFS disability. In using this booklet, you should first attempt to document your CFS disability according to the listed requirements of the new Ruling. If you are unable to document any or more than a few of the listed requirements, then you and your physician(s) should as fully, and in as much detail as possible, document your CFS according to the information and material in this booklet. The new Ruling also explains how to document your inability to work, as well as your limitations in daily life. Please note carefully, in the following section, the **importance of frequent doctors visits and the charting of signs and symptoms during these visits.**

Please be aware that the new Ruling establishes the most current disability requirements for CFS. Therefore, some of the information in this booklet has been superseded by the Ruling. However, even when an individual is able to qualify strictly according to the letter of the Ruling, much of this booklet's information can be as a means of explaining how to more specifically document the CFS disability according to the Ruling. The booklet's material will be even more important to those who must take advantage of the Ruling's allowance of unlisted findings and tests "**which are consistent with medically accepted clinical practice and consistent with other evidence in the case record.**" The material in this booklet has been developed over a period of years and so should be helpful in establishing a case when unlisted tests and findings are needed. When dated information in this booklet is clearly at variance with the Ruling, the instructions of the Ruling should be followed.

**Social Security Administration issues a major new ruling affecting all CFIDS Disability claims and reviews.**

On April 30, 1999, the Social Security Administration issued an extremely important new ruling.

**"Social Security Ruling, SSR 99-2p.; Titles II and XVI: Evaluating Cases Involving Chronic Fatigue Syndrome (CFS)."**

**Overview of the Ruling:**

This ruling sets new and more specific requirements for the medical evidence and documentation necessary to succeed in obtaining disability benefits or in maintaining one's benefits after a review. The new ruling is an attempt to clarify more specifically how Social Security examiners and adjudicators should evaluate CFS claims and reviews.

**The ruling explains exactly what medical evidence doctors should submit and how they should submit it; what laboratory tests will establish a case of CFS; and what documentation doctors, patients and others should provide as evidence of the patient's inability to work.**

Until this ruling, the guidelines for evidence and documentation necessary to establish a disability claim have not been clearly spelled-out; the new Ruling is an effort to give examiners clearer rules and guidelines for deciding on claims and reviews. The new Ruling is binding at all stages of the disability process: initial application, reconsideration, and



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administrative law judges -and it applies when SSDI recipients are periodically reviewed.

The new Ruling, without doubt, will become "the book" by which agency staff approve or disapprove claims and reviews. On the one hand, doctors and patients may find it more difficult to submit acceptable evidence, since the Ruling has limited the listing of CFS medical findings and laboratory tests -- examiners will often want to stick narrowly to the specified listing. **On the other hand, the Ruling does leave open the use of unlisted findings and tests "which are consistent with medically accepted clinical practice and is consistent with other evidence in the case record."** So patients, their doctors and attorneys will likely find themselves pressing examiners and judges to accept evidence which is valid but not specifically listed.

All the difference will be made on how rigidly or flexibly Social Security implements the guidelines and whether or not the CFIDS community both works with and presses Social Security to assure reasonable flexibility. Unfortunately the Ruling has the potential to make it tougher for disabled CFS patients to obtain or maintain their benefits. As ever, as CFIDS patients, we face a changing situation; we simply and calmly will have to work with this new situation to make it better.

**Establishing CFIDS as a Medically Determinable Impairment:**

The following is a summary of the Ruling. The evaluation of a claim or review consists of a series of steps or hurdles, each of which must be cleared in order to successfully obtain approval of benefits or of a review.

The first hurdle the CFIDS patient must clear is obtaining a finding that he or she has a "medically determinable impairment." In other words, the patient must, to Social Security's satisfaction, prove he or she has CFIDS. How is this done? The Ruling states: "CFS constitutes a medically determinable impairment when it is accompanied by medical signs and symptoms and laboratory findings." The Ruling notes that under the CDC case definition a person may be diagnosed on the basis of reported symptoms alone. However, this level of diagnosis is not acceptable to Social Security; to document a CFS diagnosis, verifiable evidence of more objective signs and symptoms must be submitted.

To clear the first hurdle -- establishing CFIDS as a medically determinable impairment -- specific medical signs and laboratory findings must be submitted. The Ruling next lists the signs and findings it will accept, but not before stating, fortunately for patients, "...the medical criteria below are only examples of signs and laboratory findings that will establish the existence of a medically determinable impairment...[medical research may find] additional signs and laboratory findings...the existence of CFS may be documented with medical signs and laboratory findings other than those below, provided that such documentation is consistent with medically accepted clinical practice and is consistent with the other evidence in the case record."

Doctors providing medical evidence for CFS patients will have to explain

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and justify the use of other medical signs and laboratory findings in supporting their patients' applications.

**Medical Signs and Symptoms:**

The Ruling then lists medical signs: "...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:

\*Palpably swollen or tender lymph nodes on physical examination;

\*Non-exudative pharyngitis;

\*Persistent, reproducible muscle tenderness on repeated examinations, including the presence of positive tender points;

The Ruling here notes the overlap of symptoms between CFS and Fibromyalgia: "but individuals with CFS who have tender points have a medically determinable impairment."

The ruling also notes the overlap, and therefore the need for further diagnostic differentiation, among CFS, Gulf War Syndrome, Multiple Chemical Sensitivity and Depression.

I will discuss below the type of documentation of medical signs the Ruling requires physicians to provide, but note especially here that the Ruling requires documentation in the clinical record of signs over at least 6 consecutive months.

**Laboratory Findings:**

Next, the Ruling lists laboratory findings that, if found, "...establish the existence of a medically determinable impairment in individuals with CFS." The Ruling does provide flexibility: "It should be noted that standard laboratory tests in the 'normal' range are characteristic for many individuals with CFS, and should not be relied upon to the exclusion of all other clinical evidence..."

The issue here is the extent to which examiners will heed this cautionary directive.

The listing of acceptable lab tests is as follows:

\*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 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;

\*Other laboratory findings ("medically accepted clinical practice and

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consistent with other case evidence"), for example:

+abnormal exercise stress test

+abnormal sleep study

The EBV titer threshold numbers are so extremely high as to have no diagnostic purpose for selecting cases of CFS. One can only wonder as to why those constructing the ruling chose these numbers.

Only in a percentage of CFS patients will MRI brain scans show abnormalities: punctate white spots. However, a patient showing abnormalities on one scan will often on a second scan show perfectly normal results. Therefore, such scans are likely diagnostic only in a minority of cases. Many patients, however, not showing diagnostic results on other tests may feel compelled to obtain an MRI in an effort to document their illness. MRIs are costly, and without insurance, beyond the reach of many patients.

A proportion of CFS patients have neurally-mediated hypotension. Research has not yet determined if this is a low or high proportion. According to Johns Hopkins researchers, protocols for correct use of the tilt table test in CFS are not widely followed --there is also disagreement as to which protocols are diagnostic.

Tilt-table tests are expensive and may not be reimbursable. Patients seeking the test would have to receive the test from a physician following reasonable protocols. Clearly, in the near future, only a minority of patients will have access to proper testing. Yet patients, in an attempt to document their CFS, may feel forced to try to obtain the test. The Ruling does allow for an alternative test which might include the "poor man's tilt-table" : the taking of blood pressure sequentially --lying down, then immediately after standing, and then 3 minutes later, standing again.

The exercise stress test may or may not be abnormal in a CFS patient. Sleep studies are, perhaps, the test most likely to be abnormal, but again this test may not be accessible to many patients.

Overall, the lab tests listed will be difficult for most CFS patients to obtain and will not be diagnostic in a substantial percentage of cases.

### **Cognitive and Mental Findings:**

Next, the Ruling lists mental findings that will establish a case of CFS as medically determinable. These findings fall within two diagnostic categories: neurocognitive impairment and mental disorders. Symptoms of neurocognitive impairment include the familiar cognitive symptoms: memory problems, visual-spatial difficulties, calculation, concentration, etc.

The Ruling states "...when ongoing deficits in these areas have been documented by:

\*mental status exam (a medical sign)

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\*psychological testing (a laboratory finding)

[Such findings] ...establish a medically determinable impairment. "

It is widely known that neuropsychological testing, as opposed to psychological testing, is the proper tool for diagnosing CFIDS. General psychological testing can be misleading diagnostically. Moreover, neuropsychological testing will only be diagnostically helpful in the hands of an experienced tester familiar with CFS. In the wrong and inexperienced hands such testing may falsely indicate a psychological disorder. Neuropsychological testing from an experienced CFS tester is probably not easily available in many parts of the U.S. Such testing is also relatively expensive. Yet obtaining the proper neuropsychological testing may be one of the best ways, under these guidelines, to provide a positive laboratory finding.

The Ruling further states that individuals with CFS may show medical signs which indicate a mental disorder, such as anxiety or depression. When such signs are adequately documented, a medically determinable impairment is established. In cases of CFS, patients often are anxious or depressed as a result of their illness (secondary depression). In these cases, medical findings would be diagnostic if correctly interpreted as connected to and confirming CFS. Such findings, however, in the past, have been used to negate a CFIDS diagnosis in favor of "psychological" illnesses.

**Documenting Medical Signs and Symptoms and Laboratory Findings:**

The ruling clearly states that, "appropriate documentation should include a longitudinal clinical record of at least 12 months prior to the date of application, unless the alleged onset occurred less than 12 months in the past... [moreover] the record should contain detailed medical observations, treatment, the individual's response to treatment, and a detailed description of how the impairment limits the individual's ability to function over time."

("When the alleged onset of disability secondary to CFS occurred less than 12 months before adjudication, the adjudicator must evaluate the medical evidence and project the degree of impairment severity that is likely to exist at the end of 12 months. Information about treatment and response to treatment as well as any medical source opinions about the individual's prognosis at the end of 12 months are helpful in deciding whether the medically determinable impairment(s) is expected to be of disabling severity for at least 12 consecutive months...)

**Patient's responsibility to work with his/her physician(s) to develop and maintain a detailed and complete record in which entries are made at sufficiently frequent periodic intervals:**

The Ruling requires documentation of medical signs, symptoms, laboratory findings and observations as to how the patient's illness limits his/her ability to function over time. The Ruling is clear that the doctors' office notes, record, and charts are primary evidence. Most of us when we first become ill never imagine that at some point we may need to apply for

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disability, whether it be Social Security or through our employer. Nevertheless many CFIDS patients, at some point, find that they must seek disability benefits.

Therefore, especially if a patient is considering applying and also if a patient is already receiving benefits (anticipating a review), he or she must alert and actively work with his/her physicians to build a comprehensive clinical record that records each and every medical sign, symptom and laboratory result during or following each office visit. The Ruling makes clear that prior to or during an application or review period, a 12 month consecutive clinical record is needed. Therefore, anticipating or during such periods, patients must make efforts to visit their doctors frequently (6-8 weeks) in order to build the necessary record and be in the best position to document their illness. During this period, patients should discuss with their physicians which lab tests would be appropriate for the documentation of their CFS.

**Severity of the Illness:**

Once a case of CFS is found to be medically determinable, then the illness's severity (the second hurdle in the process) must be established. Severity is determined by the totality of medical signs, symptoms, and laboratory findings and the effects of the impairment on the ability to function. The adjudicator proceeds to evaluate the intensity and persistence of the symptoms. In making a determination of severity, the adjudicator will evaluate the patient's allegations of pain, fatigue, symptoms of neurocognitive problems, and other CFS symptoms. If the CFS symptoms are found to cause "...a limitation or restriction having more than a minimal effect on the individual's ability to perform basic work activities. the adjudicator must find that the individual has a 'severe' impairment." The Ruling also notes that individuals with CFS who have psychological manifestations related to CFS should be evaluated as to the severity of these symptoms in relation to the severity of a "listed mental disorder. "

**Documenting the PWC's (person with CFIDS) Inability to Work:**

Since CFS itself is not on the Listing of Impairments (subpart p of 20 CFR 404) and the finding of severity equivalence between CFS and a listed impairment is problematic, most CFS cases must proceed to the 4th and 5th steps in the evaluation process. These steps or hurdles involve the assessment of the claimant's residual functional capacity: the patient's ability to work. All of the patient's symptoms must be considered as to the their effects on the patient's functional capacities. Generally, "...the conclusion about whether...individuals [under age 50] are disabled will depend on the nature and extent of their functional limitations ."

The patient's residual functional capacity, according to the Ruling, should again be documented in his/her longitudinal clinical record. The patient and doctor should work, over time, to build this record --with an eye to both obtaining benefits and to future reviews.

As discussed above, Social Security emphasizes a detailed record for a 12 month period preceding the month of application (or a review.)

Treating and medical sources should include the following assessments in

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the longitudinal clinical record: "...extent and duration of an individual's impairment(s), including observations and opinions about how well the individual is able to function, the effects of any treatment...and how long the impairment(s) is expected to limit the individual's ability to function. Opinions from an individual's medical sources, especially treating sources, concerning the effects of CFS on the individual's ability to function in a sustained manner in performing work activities or performing activities of daily living are important...In this regard, any information a medical source is able to provide contrasting the individual's impairment(s) and functional capacities since the alleged onset of CFS with the individual's status prior to the onset of CFS will be helpful..."

**Letters Supporting Disability Claim:**

The Ruling requires that when an individual's statements "...about the intensity, persistence or functionally limiting effects of symptoms are not substantiated by objective medical evidence, the adjudicator must consider all the evidence in the case record, including any statements by the individual and other persons concerning the patient's symptoms." [Statements]"...assessing an individual's ability to function on a day-to-day basis and to depict the individual's capacities over a period of time" should be obtained from: 1) neighbors, family, friends, clergy; 2) past employers, rehabilitation counselors, school teachers concerning the person's ability to function in the work place or the relevant facility; 3) other health care providers, e.g., nurse practitioners, physician assistants, naturopaths, chiropractors, therapists; 4) others with knowledge of the patient.

**Examination by Social Security Doctors and Claims of Conflicting Evidence:**

Two other portions of the Ruling should be noted. First, the section on Consultative Examinations. If the adjudicator finds that the evidence submitted is inadequate to determine whether the individual is disabled, then the adjudicator must **first** recon tact the patient's physician(s) to find out if the additional information needed is readily available.

If not the agency will obtain a consultative examination from a medical source of its own choosing. Thus, it behooves patients to work with their physicians to submit comprehensive medical evidence and documentation of disability.

Second, when conflict develops between conflicting medical evidence in a patient's record, then Social Security is required to give deference to medical opinions from the patient's treating sources.

**Conclusion:**

This Ruling will become the new basis for evaluating CFIDS disability claims and reviews. Anyone filing a claim or who is being reviewed should be familiar with it and, to the best of their ability, provide as much as possible of the evidence required by the Ruling.

Patients and their doctors will have to propose and press for the

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acceptance of other diagnostic medical signs and symptoms and laboratory tests as allowed by the Ruling.

### **Letters from your Primary Care Physician (continued):**

Now that you are familiar with how CFIDS is formally diagnosed, and how the new Ruling affects the Social Security evaluation of CFIDS, we turn again to the needed letters of documentation from your primary care physician.

It is not enough for your doctor in his/her letter simply to state that you have CFS and leave it at that. First, your doctor should document the relevant findings produced by the history, physical, and other examinations and the laboratory testing. In general, any lab tests which are indicative of infection, immunological or other neurological abnormalities should be submitted.

Dr. Anthony Komaroff, a leading specialist in CFS, cites the following laboratory abnormalities as supportive of a CFS diagnosis:

### **Table 1**

#### **Laboratory Abnormalities and Chronic Viral Fatigue Syndrome (CFS)\***

Mild leukopenia (3000-5000/mm)  
Moderate monocytosis (7%-i 5%)  
Relative lymphocytosis (>40%)  
Atypical lymphocytosis (1%-20%)  
Slight elevation in SGOT and SGPT  
Erythrocyte sedimentation rate unusually low (0-4mm)  
Partial reduction in immunoglobulins  
Circulating immune complexes (low levels)  
Increased CD4/CD8 ratio  
EBV antibodies:  
    Viral capsid antigen - IgG > 1:640  
    Viral capsid antigen - IgM - not detectable  
    Early antigen ~ 1:40  
    EB nuclear antigen < 1:5

*\* It is unusual for more than two or three of these findings to be present in any single patient.*

Also see Appendix II for a further list of diagnostic tests compiled by Dr. Charles Lapp. Any tests falling within the above ranges should be submitted by your doctor.

In most cases the physician would then document that the evaluation had found no illness or condition that would exclude a diagnosis of CFS and therefore would provide an alternative diagnosis. (If the individual clearly has CFS and there is the presence of an exclusionary condition, the doctor can still provide a CFS diagnosis, see above for discussion.) Your doctor should list each and every one of your

symptoms, past or present (with this illness, symptoms can vary over time). The doctor should then describe the character and date of onset, and the progression of your illness since onset, including changes in and intensification of the illness and symptoms over time. Special attention should be given to describing the severity, frequency, duration, and the recurrence of the major symptoms. In addition to your doctors' letters documenting your symptoms, you may as part of your application complete and submit the CFIDS symptom checklist (see Appendix II.) You and your doctor may also wish to use the list as an aid in compiling and documenting your symptoms for his or her letters and reports. Also within his or her letter, the doctor may wish to include any other diagnoses found during the evaluation phase (including those illnesses or conditions that fit the criteria that do not adequately explain chronic fatigue. These are the so-called inclusive diagnoses whose presence does not rule out a diagnosis of Chronic Fatigue Syndrome - see above discussion.) Such conditions may include Fibromyalgia, chemical sensitivity disorder, unresolved Lyme Disease, etc. The question often arises as to whether transient and non-serious secondary depression should be documented. Please see discussion in Appendix IV for a full discussion of this issue. Also in cases in which an individual clearly has CFS, but there is an exclusionary condition (example: A major depression which was fully resolved in the past), it would seem better for the patient to find a physician who can provide a diagnosis of CFS rather than receiving a diagnosis of idiopathic chronic fatigue since Social Security has no diagnostic listing at this time for idiopathic chronic fatigue.

Your doctor should specifically describe all treatments, including medications which have been prescribed either currently or in the past. The results of each treatment should be reviewed. Medication for dealing with the secondary depression (depression caused by the illness) often does not help any of the other CFS symptoms - this should be noted if it is in fact the case.

The preceding discussion has focused on your physician's letter. A number of attorneys with wide experience in representing Social Security Disability cases stress the increasing importance placed by Social Security on **your doctor's treatment notes** as a means of verifying your disability.

Attorney Fay E. Fishman is a Civil Practice attorney, with an emphasis on Social Security, from Minneapolis, Minnesota. She has handled many successful appeals for persons with CFIDS. She stresses that the doctor's regular treatment notes can be a critical element in either helping or hurting the patient's disability claim. The patient should suggest to the doctor during the course of treatment that the doctor should provide in his or her treatment notes the following information as necessary documentation in the event of a future disability claim.

Attorney Fishman writes:

First, on each visit, examinations which document the fatigue and symptoms of CFS [listed in the new Diagnostic Criteria, see Appendix I,] must be performed. Temperatures should be taken and noted, throats must be examined, and nodes must be palpated.

Second, the symptoms complained of by the patient must be noted (including night sweats, sleep disturbances, body aches, extreme fatigue, nausea and cognitive dysfunction, etc.) at each examination. The comment that, "The patient remains unchanged," does not help a claim. Further comments such as, "the patient is somewhat improved," or "patient's energy level has increased" without further explanation can hurt a claim.



Again, medical records in the legal system are primary evidence, which determine whether a patient can collect disability benefits.

In an article entitled "*Helping Fibromyalgia Patients Obtain Social Security Benefits*" by Attorney Joshua W. Potter, published in the U.S.A. *Fibrositis Association Newsletter*; Attorney Potter writes the following:

When a physician recognizes that a patient may become a candidate for Social Security Disability payments, chart entry should be made in detail... Every patient visit should result in entries concerning physical capacities for lifting, bending and carrying (verified with measured weight); time durations for sitting, standing and walking (by history); the nature, location and intensity of pain (by history); psychosocial and adaptive behavior, including the ability to interact appropriately with others, follow instructions, and adhere to a regular work schedule; and the complex of expressive symptoms.

**Important:** At the end of this booklet you will find Appendix II entitled, "*Helping Your Doctor Prepare Your Medical Report.*" This Appendix has Recommended Documentation of CFS Disability to be submitted to Social Security and/or for Private or Employer Disability.

Based on a number of disability lawyers' extensive experience adjudicating CFS cases, the Memo details the specific documentary evidence that should be submitted to Social Security (and other disability carriers). Following the Memo's suggestions should definitely strengthen a claimant's case.

The Memo provides very useful and helpful suggestions to Doctors on the type of documentation to include in the Medical Report. Moreover, the Memo also includes the actual legal language that would be helpful for the Doctor to use in documenting your disability. Give your doctor(s) a copy of the Memo.

Also included in the Appendix are several sample doctors' letters which help demonstrate how a strong and effective letter can be written. However, please read the instructions concerning these letters carefully before showing the letters to your doctor, since each letter lacks certain necessary information - only by looking at the combination of the letters is it possible to obtain a picture of what a model letter should look like.

Finally, another section of Appendix II explains how you can take some initiative (depending on how sick you are) in helping your doctor prepare the strongest and most effective report possible.

One suggestion is to ask your doctor(s) to let you see his/her letter (and the Social Security questionnaire) before s/he mails them to Social Security. If the letter or questionnaire isn't strong enough, then you can ask your doctor to consider revising it, based on your suggestions. In any case, you should be sure to ask your provider to send you copies of all letters and records submitted to Social Security. It is important for you to have copies for your records.

## **Supplementary Diagnostic Materials**

Letters by specialists supporting your diagnosis, including the results of specialized neurological, hematological, immunological, or neuropsychological testing should be submitted. Whether or not you

are able to submit the documentation requested by the new Ruling, the supplementary testing results discussed here should strengthen your case.

Neuropsychological testing is achieving importance as a CFS diagnostic tool and is recognized as such by Social Security. This type of test, when administered and interpreted by a skilled specialist, can distinguish between symptoms caused by psychological disorders and symptoms caused by more organically-based illnesses such as CFS. See the appendix IV on *neuropsychological testing and depression*. **Very Important:** Interpretation of these tests must be done by a specialist experienced in analyzing the tests in relation to CFIDS; otherwise the tests could be interpreted incorrectly with potentially negative effects on the disability application.

The CDC diagnostic criteria require that a CFS diagnosis rule out primary depression as an alternative diagnosis. If necessary, your doctor, in his letter, may state that *your illness and symptoms are caused by CFS, that your symptoms cannot be accounted for by an alternative diagnosis of primary depression*. (Neuropsychological testing can help differentiate CFS from a diagnosis of primary depression.)

Once a firm diagnosis of CFS is established, the doctor may document any diagnosis of secondary depression caused by the patient's struggle with the effects of CFS. It is very important that the doctor, when discussing depression, distinguish between primary depression (which would cause your symptoms) and secondary depression (which would be a result of your symptoms). *See the appendix on depression* for the advisability of including a diagnosis of secondary depression in your medical report.

If you are applying for private disability, you must read item 6 in section B of Appendix IV as well as appendix VII on Private Disability.

Finally, when you apply for reconsideration or for an appeal hearing, you should ask your doctor for follow-up letters to supplement his original evaluation - these letters would describe any new diagnostic findings and would describe changes in the illness and symptoms since the last letter.

**Very Important Note on Multiple diagnoses:** Your doctors' letters should also fully document all other medical conditions which, in addition to CFS, contribute to your disability. Often your case will be stronger if there are additional diagnoses which are not at variance with the CFS diagnosis and which increase your overall level of disability.

## **Documenting Your Inability to Perform Tasks ("Residual Functional Capacity")**

In the second part of your primary physician's letter, your doctor must document in some detail how your illness prevents you from performing even light, sedentary, part-time work on any continuing basis.

The doctor should describe how and to what extent your illness and symptoms limit your ability to carry out necessary activities and tasks, including household and personal care activities, occupational tasks, and social activities.

**Important:** Please refer first to the new Ruling for guidelines on how you and your doctor(s) should

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document your inability to work and perform daily tasks. (Please see above the section “Documenting the PWC’s inability to Work” in the summary of the Ruling.) Use the rest of the information in this section (and Appendix II) as a supplement, when applicable, to the guidelines set forth in the Ruling. These guidelines (the Ruling’s guidelines first) will directly assist your doctor(s) in documenting (in his/her medical reports) your inability to work. The guidelines specify the types of limitations and incapacities your doctor(s) should document in the report, so make sure you give a copy of these guidelines to your doctor(s).

The doctor should assess your inability to perform these activities and tasks according to both the intensity and duration of the task. S/he should note how the intensity and duration of various tasks cause your symptoms to become worse. Special emphasis should be given to describing the intensity and type of the *pain, fatigue, and disorientation* caused by your efforts to carry out various activities.

The doctor should document the chronicity of these various limitations - how long these limitations have lasted - and summarize how your capabilities have changed or become more and more limited as your illness has progressed.

Your doctor should give several *specific examples* of the limitations in your daily household, personal care, and social activities caused by the illness - as well as a description of the detrimental effects (including pain, fatigue, disorientation, and needed recovery times) resulting from such efforts. Such examples might include your difficulty performing basic household tasks such as washing dishes, walking to the store, cleaning the house, etc. If you are forced to wake up late or to lie down or nap at intervals during the day, this should be noted. If ongoing activities beyond a couple of hours cause your symptoms to worsen, specific examples should be given. If your social activities have been severely curtailed by the illness, examples should again be given.

The doctor should also summarize your limitations regarding your present capacity to perform occupational tasks, related both to your former employment and your ability to perform light, sedentary work, part-time on an ongoing basis. If you have neurological impairments the doctor should assess limitations in concentration and short-term memory. The doctor should assess the effects of pain and fatigue resulting from various activities, including intermittent or prolonged sitting, lifting, walking, etc.

It would be helpful if the letter describes how your ability to perform at your job became more and more difficult as your illness developed.

Assuming your limitations are severe and chronic, your doctor should state that you are disabled and completely unable to work, and that this situation is not expected to change for at least a year.

In most cases, doctors will not describe most of your functional limitations in great detail but do ask him/her to summarize your limitations - especially with regard to chronicity and pain - according to the instructions above, and to give several examples

The Mass. Disability Law Center, in its booklet, "How to Secure and Protect your Social Security Benefits," provides the following short checklist to help in evaluating your inability to work:

## **How does your condition affect:**

- your daily activities
- your ability to stand, sit, or walk for a long period
- your ability to lift or carry weight
- your ability to understand, carry out, and remember instructions
- your ability to respond appropriately to your supervisor and co-workers
- your other physical or psychological functional restrictions, and
- your ability to adjust to the stress of a work environment.

You may want to give a copy of this checklist to your doctor. (copy in Appendix II.)

## **Cognitive Dysfunction: Its Limiting Effects on a PWC's Ability to Work**

Neurological impairments and cognitive dysfunction impairments of thinking, memory, concentration, etc., seriously affect many CFS patients. These impairments can profoundly limit a person with CFIDS' (PWC) ability to work.

Factors such as paying attention and concentrating on the job task, performing job activities within a schedule and at a consistent pace, maintaining regular attendance and being punctual, remembering locations and work-like procedures can be severely impacted by cognitive dysfunction.

Adequately documenting these "non-exertional factors" may be crucial to winning a CFS case.

Social Security evaluates disability claims through a chart (GRIDS system) which enumerates major functional and vocational patterns and into which a claimant's residual functional capacity and vocational patterns are inserted. Ordinarily, under this system, anyone found capable of light work is not found disabled.

However, when there are "non-exertional factors," the GRIDS system cannot be routinely relied upon. Non-exertional factors, if properly applied, can take the application off the grid, thereby relaxing the criteria for claim approval.

Therefore, it is very important for providers to document neurological impairments and cognitive dysfunction in detail. Special attention should be given to showing how these impairments contribute to the person's inability to work (non-exertional factors.)

Any supplementary letters describing your occupational and other functional limitations would be helpful if obtained from former employers, rehabilitation or occupational specialists - or any other person (including family and friends) in a position to make such observations.

## **V. Your Own Description of the Disabling Effects of Your Illness**

As part of the application process (and also as part of the various appeal stages), the applicant must give a full description of the disabling effects of the illness and its symptoms on the different areas of his/her daily life, including personal care, household and social activities. This description should be given in detail: one approach is to list each and every symptom and to describe how each symptom limits each of the tasks you perform each day. You may find the CFIDS symptom checklist (see Appendix II) helpful in the process of compiling your symptoms and their effects. It is also advised that you take a fairly bad day and go from hour to hour documenting how each symptom impairs your living. You may wish to keep a diary of your illness to facilitate your documentation of impairment - several diary-like formats are available for documenting the effects of your illness. (See the resources appendix.) These records may be submitted directly to Social Security.

*Note:* In answering questions on the Social Security application, it is recommended that while applicants should fully document their illness and disability, they should do so only in the length of words required to provide the necessary and essential information and detail. Thesis-like answers amounting to many pages in response to each question will only cause Social Security to question whether the applicant might be able to work as a writer, i.e., that the applicant is not disabled.

If you completed the application entirely by yourself, it is helpful to note how many sessions, of what length, over how many days, were required for completion - and why - due to fatigue, symptoms, cognitive dysfunction, etc. Several sentences should suffice.

Also if you were too sick to complete the application by yourself, and needed help in preparing or transcribing your answers, you should explain this to Social Security. By doing so, you will make Social Security aware that you are disabled to the point you are unable to do this amount of work yourself. Still, even with the help of another, do not send Social Security a lengthy number of pages.

Naturally, if you send a diary, you will probably send more pages, but note that the diary was compiled over a number of months. You should also highlight the essential material in the diary as no Social Security examiner has the time to read a mountain of detail.

Also, on the above issues, see item 11 in the third memo, Appendix III.

## **VI. Contacting Your Congressman about your Social Security Application**

You may wish to inform your congressman that you are applying for Social Security Disability either at the time you apply or at any time during the application process (including during any of the appeal stages.) Your congressman is a member of the U. S. House of Representatives in Washington, D.C. After you call your Representative, he or she will contact the Social Security Administration to ask that your case be handled in a fair and timely manner. The decision on your case will not be influenced in any way by the fact that you contacted your congressman; however, there may be fewer delays in your obtaining a decision since Social Security will be aware of your Congressman's interest. It is not at all necessary for you to contact your congressman in order to obtain disability benefits, but doing so may provide some advantage in obtaining a more timely decision, especially if you are encountering an

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How to Apply for Social Security Benefits if You Have Chronic Fatigue Syndrome

unreasonable delay.