

**HOW TO APPLY FOR
SOCIAL SECURITY DISABILITY BENEFITS
IF YOU HAVE
MYALGIC ENCEPHALOMYELITIS/
CHRONIC FATIGUE SYNDROME
(ME/CFS)**

With Additional Information on Applying for Benefits
If You Have Fibromyalgia

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Massachusetts ME/CFS & FM Association
2021

DISCLAIMER

The Massachusetts ME/CFS & FM Association serves as a clearinghouse for information about 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 ME/CFS&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 very 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.

A sick individual will find it difficult to read through this booklet except during times when they are feeling better ; this book is meant to be read in steps according to what you need to know, according to what step of the Social Security process you are on.

Applying for Social Security Disability is often a long-haul process, so take it one step at a time, and learn what you need to at each stage. Just learn at your own pace – or if you have a family member or friend who can help you learn from this book, all the better.

Obviously this book is meant to be comprehensive – so as not to leave out anything that would give you the best chance to win your case.

The book is not meant to be read through entirely. You should use the Table of Contents to find the information you need as follows:

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 I for ME/CFS; and Appendix III for fibromyalgia. ***Also you should absorb Appendix IV, since it gives you a wealth of information on how to document the illness.*** If you already have an up-to-date and well-documented ME/CFS diagnosis, you may want to skip the section on “Obtaining a ME/CFS Diagnosis.”

It is very important that everyone read, no matter what stage you’re involved in, Appendix I on the **2014 Social Security ME/CFS Ruling** because it’s so important. Also, you must read the Social Security Guidance for providing medical evidence: **“Providing Medical Evidence for Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome”**, and make sure your physician(s) have a copy.

For Fibromyalgia sufferers many sections of this booklet apply generally to fibromyalgia disability applications. There are also sections that apply specifically to FM, particularly the **2012 Fibromyalgia Social Security Ruling** (see Appendix III.)

If you reached the Administrative Law Judge hearing stage for ME/CFS, turn to Appendix I, IV and V. If you’re getting reviewed when you are on Disability, turn to Appendix VIII.

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

If you are applying for disability through your employer, read Appendix IX and Appendix IV. You should also look at the section on Long-Term Employer Disability on our website: <https://www.massmecfs.org/disability>.

Also, on our website we have an entire disability section with many important articles relating to many different aspects of needed assistance for those who lose employment because of the illnesses. The disability home page is at <https://www.massmecfs.org/disability>

Also, there is a specific section on Social Security disability with articles and information that are an important supplement to this Booklet. Applicants should check this section out at <https://www.massmecfs.org/social-security-disability>

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 ME/CFS, that it has helped many. I hope it helps you.

Ken Casanova

APPENDIX II

OBTAINING A CFS DIAGNOSIS USING THE 1994 CDC CFS DEFINITION

Note: *This section detailing diagnosis under the 1994 CDC definition is long and detailed, and in many ME/CFS cases at some point may no longer apply to disability applications since portions of the Criteria are outdated and may be superseded by the 2014 Ruling and the newer Canadian and International Criteria, as well as the newer 2015 IOM-CDC Criteria. However as yet the Social Security Administration has not, as far as we know, accepted the new 2015 IOM-CDC Criteria. The SSA would have to issue a new Ruling to recognize the new Criteria. It is important to know how the illness is currently diagnosed for Social Security and may be relevant for LTD benefits*

As already discussed, the SSA Ruling still recognizes the 1994 CDC definition as the primary method of diagnosis. For disability purposes in 2021, a physician could state s/he has diagnosed the illness according to the 1994 CDC definition; the 2003 ME/CFS Canadian Definition; the ICC definition and even the 2015 CDC definition (as long as least one of the first three are included.)

The 1994 Centers for Disease Control Diagnostic Criteria for Chronic Fatigue Syndrome, was published in an article, "The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study," published in the *Annals of Internal Medicine*, December, 1994.

The 2003 Canadian Criteria was published under the title: "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols," in the *Journal of Chronic Fatigue Syndrome*, Vol. 11, Number 1, 2003. This definition is far superior to any previously widely-disseminated 1994 CDC definition and will probably be used by some doctors to make clinical diagnoses.

We do include this section because some of the issues and exclusions raised by the 1994 CDC Criteria may arise with physicians (and even Social Security) who are only familiar with this older definition.

Note: This is a long and detailed section, so readers may wish to look through the rest of the booklet and then come back to further understand more of the diagnostic issues.

Obtaining a well-documented ME/CFS or Fibromyalgia diagnosis is a crucial first step in obtaining disability benefits. Unfortunately, many patients still have difficulty obtaining a diagnosis because their physicians do not know how to diagnose or lack confidence in making the diagnoses.

Physicians who are not well-informed about the illness may benefit from reviewing the 4 different diagnostic criteria for ME/CFS and CFS. The 4 Criteria can be found through the links on page 17 of this booklet. For Social Security applications it is prudent for the illness to be diagnosed first

with the 1994 CDC Criteria and then to be supplemented with full documentation using the 2003 Canadian Criteria or the 2011 ICC Criteria. In 2020, Doctors will begin to be exposed to the 2015 definition.

Here we will review the diagnostic process under the 1994 Case definition and Diagnostic Criteria.

Under these 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 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 ME/CFS in obtaining a diagnosis and in applying for Social Security. By understanding the potential pitfalls of psychiatric evaluation, an informed individual with ME/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. (The distinction here between the current name ME/CFS and the Social Security name of CFS may be noticed.)

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 VI.

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 ME/CFS sufferer. Many ME/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 ME/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 ME/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...

...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 continuing text of this section of the CDC criteria discourages use of further tests such as MRIs or other imaging, immune, neurological, sleep studies, endocrine testing.

This portion regarding excluded tests is superseded by the 2014 Ruling and should be disregarded.

The second phase of the diagnostic process may be called the *Exclusion/inclusion 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 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)²] 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 non-melancholic 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 CDC 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 post-exertional 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. 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.

Special note: In 2021 the new Ruling and newer definitions pretty much have superseded the Idiopathic Chronic Fatigue diagnosis. Such a diagnosis would only very rarely be used, and given its uncertainty might not yield a positive outcome. In any case, any medical diagnosis must demonstrate severe disability. The idiopathic chronic fatigue diagnosis, for all practical purposes, except in rare instances, may be generally ignored.

In such circumstances the diagnostic method would be to evaluate according to the 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 find the 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 IV.)