

**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*  
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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 VI

### *The Use of a Diagnosis of Depression or Other Mental Impairments in a ME/CFS Social Security Application*

#### **Introduction**

The following section will review, in detail, the issues and problems of introducing a diagnosis of depression or mental impairment into a CFS disability application.

The purpose of this section is to acquaint the reader with the arguments for and against citing secondary depression or other mental impairments in an application.

One school of thought, previously, and perhaps still represented by some Legal Services disability attorneys is that the documenting of secondary depression or other mental impairment in a CFS application may aid acceptance of the disability claim.

The other school of thought represented here by Attorney Bernard Kansky is that the use of these diagnoses should be avoided, if possible.

This section also discusses the problems that can develop between attorneys and ME/CFS patients when mental impairments are used in disability applications.

As discussed below, there are only 3 bars to the inclusion of secondary depression in a CFS Social Security application: 1) poor documentation which allows the question of primary depression to surface, 2) the issue of stigmatization, 3) the issue relative to private disability: if the claimant is receiving, or might in the future receive private disability, **any question of depression might be used to curtail benefits**. If the issue of private disability does not enter into the picture, and a secondary depression due to ME/CFS is well-documented, the applicant must determine if physical signs and lab tests sufficiently establish the disability without the use of secondary depression. If not, the applicant might be well-advised to think carefully before rejecting the use of secondary depression as a means of establishing a ME/CFS claim.

#### ***A. The position that there is a positive use of secondary depression and mental impairment in a Social Security disability application***

Obtaining Social Security disability benefits on a physical diagnosis alone can be difficult; although a well-documented, disabling physical diagnosis is often approved at the hearing stage. A physical diagnosis of disability is often more difficult to prove because of Social Security's use of the "GRIDS system" of disability evaluation. The "grid" is an evaluation tool: the claimant's

diagnosis, age, employment history and work potential are plugged into the grid which then determines whether or not the claimant is disabled. Establishing even an obvious physical disability through the grid can be difficult -- unless the total physical disability is very well documented, claimants who are physically disabled are often rejected by the grid system. The claimant's disability application is then denied.

However, despite a rejection on a physical diagnosis alone by the grid, the patient will be given a "second chance" if the patient also has a mental impairment diagnosis, including a diagnosis of secondary depression (which is common in ME/CFS patients). With a mental impairment diagnosis, the claimant's disability is "taken off the grid," and the mental impairment diagnosis is then added as an extra disabling factor. This additional step is often enough to tip the scale so that the patient's claim is approved.

A diagnosis of **primary** depression (unless clarified as a separate diagnosis from an existing ME/CFS diagnosis) may well negate a diagnosis of ME/CFS, and therefore cause a CFS disability claim to be rejected (since primary depression often looks somewhat like ME/CFS).

However, ME/CFS patients often suffer from secondary depression: the patient is depressed as a result of the physical illness. Secondary depression is a well-known side effect of many chronic physical illnesses.

If a physician, psychiatrist, or psychologist documents that a **depression is secondary**, then such documentation will usually add weight to a CFS disability application, and thereby make approval more likely.

As discussed in the next section, the possible drawbacks of using a mental impairment/depression diagnosis are 1) a possible future stigma which could attach to the patient, especially in the areas of employment or insurance; and 2) **loss of employer-related, long-term disability benefits after two years.**

Some disability attorneys in Massachusetts have *believed in the use of mental impairment diagnoses (when such diagnoses are well-documented) as a necessary aid in gaining the acceptance of disability claims.*

Some attorneys generally have recommended further psychological testing whenever a patient's medical reports indicate a psychiatric or psychological diagnosis. The purpose of the testing is to determine and document any such diagnosis; the testing would then be submitted to Social Security as evidence of the diagnosis. These attorneys believe that looking at the whole person - physically and psychologically - is a proper and valid way of proving disability.

Special Note: For ME/CFS patients attempting to document neuro-cognitive symptoms, the best test is a neuropsychological test – not a neuropsychiatric test, nor generic psychological testing. However, neuropsychological testing on ME/CFS patients must be performed by a tester familiar

with the illness. Do not use a tester who is not familiar with the illness – no test is better than a badly interpreted test.

***Problems which may develop between ME/CFS patients and their attorneys regarding documentation or submission of mental impairment diagnoses***

Historically, problems have occurred with the use of psychological testing by some legal assistance attorneys and other attorneys. Such testing may be properly used if there is already an indication in a provider's report of possible depression or mental impairment. Unfortunately, sometimes lawyers will routinely order the testing without prior documentation that there is a possible problem. In effect, the lawyer is engaging in a "fishing expedition" - to see if there is any possible mental impairment that might be used on behalf of the client. Sometimes, the lawyer will routinely ask the client to submit to such testing during the initial client interview.

The results of such psychological testing may be accurate, consistent with a ME/CFS diagnosis, and helpful in obtaining approval of the claimant's disability. However, the results of psychological testing may sometimes present the patient with difficult problems:

- I. The testing may accurately reveal real psychological or emotional problems which the client may not wish to submit to Social Security because of possible stigmatization.
2. Sometimes psychiatrists or psychologists may make a false diagnosis. With an ME/CFS patient, such false diagnoses may consist of a) an erroneous psychiatric diagnosis as a substitute for the real ME/CFS diagnosis, or b) an additional, false psychiatric diagnosis.

**A psychological report which falsely substitutes a mental impairment diagnosis for a ME/CFS diagnosis certainly will harm a CFS disability claim.** Moreover, a false psychiatric diagnosis of any kind may itself cause real mental and emotional distress to the patient and lead to possible future stigmatization. The natural bias of some mental health professionals is toward finding mental health problems - even if they do not exist, or are minor, or are secondary to a physical illness.

In the past administrators who set policy for legal services disability attorneys in Massachusetts have clearly stated:

- a. That clients have the right to read all psychological reports that result from the testing - unless the tester indicates that the client should not see the report (not a usual procedure). In this case the attorney should tell the client to request permission from the tester for access to the report.
- b. That the client may veto submission of the psychological testing to Social Security. If the client does not want the report sent, the lawyer cannot submit it.

Still problems may sometimes develop. An attorney may believe that a report of psychological testing is vital to winning the client's case. The attorney may be concerned about the client's

reaction to the report, or may feel the client doesn't need to see the report. For these reasons, and perhaps because the attorney is overworked, he or she may simply send in the report to Social Security without first giving the client the chance to read the report. If this happens, the patient may well feel betrayed by his or her lawyer; because of the loss of trust and feelings of anger, the patient will be in a difficult position: whether to continue with a lawyer s/he no longer entirely trusts or to change lawyers in midstream (an option which at times is not easily available).

Once psychological testing is performed by a qualified provider then the results of the testing may not properly be withheld from Social Security – and such withholding might be considered fraudulent. Hence, if the attorney recommends such testing it is best to consider whether, given the possible difficulties, it should be performed.

As stated above, the use of psychiatric documentation of a secondary depression may actually help clarify a ME/CFS diagnosis, thereby increasing the client's chances of acceptance by Social Security. (Such documentation has proved helpful to CFS claimants.) Such clear documentation can, in the hands of a tester aware of ME/CFS, remove any doubts as to whether the depression is primary or secondary.

The alternate school of thought is that the use of a depression diagnosis can lead to stigmatization and is not necessary to winning if disabling physical symptoms are properly documented.

If an attorney recommends using a psychological diagnosis to support a disability claim, and the client is uncertain about submitting the diagnosis, the client should discuss his or her concerns with the attorney. The attorney may indicate that the case may be harder to win without the use of the psychological diagnosis. Or, if the attorney believes that the case cannot be won without using the diagnosis, the attorney may be unwilling to pursue the case unless the psychological diagnosis is used. After listening to the attorney, the client will have to weigh the risk of losing, against his or her reluctance to submit a psychological diagnosis. It may also be possible to obtain a second legal opinion.

However, there is a major difference between psychological/neuropsychiatric testing and neuropsychological testing. Neuropsychological testing performed by a tester knowledgeable about ME/CFS can measure organic cognitive dysfunction caused by the illness.

**Cognitive dysfunction** (memory loss, difficulty thinking, etc.) frequently affects ME/CFS patients. It is thought to result from the organic and neurological aspects of ME/CFS. Organic cognitive dysfunction does not fall into the categories of mental or emotional illness and therefore, does not carry their social stigma. **Neuropsychological testing** can distinguish between organically-based cognitive dysfunction and symptoms based on emotional or "psychological" illness. Neuropsychological testing, therefore, may aid in eliminating

psychological diagnoses and in establishing an organically-based cognitive dysfunction associated with CFS (thereby supporting a CFS diagnosis). Moreover, neuropsychological testing can document various "non-exertional factors" such as the inability to concentrate, loss of memory functions, etc. which clearly interfere with the ability to work. The importance of correct interpretation of neuropsychological testing is paramount; **the tester must be familiar with how to interpret neuropsychological tests when the patient has ME/CFS.** The patient must ask the tester beforehand if he/she is familiar with ME/CFS, and if the tester can do the interpretation in a way that takes the illness into account. Sometimes, testers unfamiliar with ME/CFS can misinterpret the tests to the detriment of the ME/CFS diagnosis.

Under the GRIDS system of disability evaluation, anyone found capable of light work is usually not considered disabled. However, when there are non-exertional factors, the GRIDS system cannot be rotely relied upon, and non-exertional factors, if properly applied, can take the application off the GRIDS system.

Factors such as paying attention and concentrating on the job task, performing job activities within a schedule and at a consistent pace, maintaining a regular attendance and being punctual, remembering locations and work-like procedures -- all these additional factors are important in determining the ability to perform substantial gainful activity,

These non-exertional elements are often crucial to a CFS claim. Neuropsychological testing can be an aid in documenting these factors. Whether or not such testing is performed, it is vital that the patient's providers document neurological/cognitive symptoms and the effects of such symptoms on the patient's ability to work.

### ***B. The case for avoiding, if possible, the use of depression or other mental impairment diagnoses in a ME/CFS disability application***

Position of Attorney Bernard Kansky of Boston, Massachusetts: Attorney Kansky has obtained a number of successful decisions for ME/CFS claimants from administrative law judges.

1. The question arises as to the necessity of introducing a diagnosis of depression or mental impairment into the record of a CFS Social Security disability claimant as a means of increasing the odds of a favorable decision.
2. There are two types of depression: primary and secondary. Secondary depression occurs frequently in ME/CFS as a patient's reaction to long-term physical symptoms. Depression is a common secondary symptom of many chronic illnesses. Primary depression is considered a separate illness with its own causative factors.
3. Both ME/CFS and primary depressive illness have a number of common symptoms (but ME/CFS has certain symptoms that are not found in primary depression). By introducing a diagnosis of depression into a CFS claim, one easily begs the question of primary depression.



The claimant may then be required to disprove the diagnosis, often having to run the gamut of consulting examiners who may further muddy the waters. Receiving disability for primary depression may be more difficult since the illness may be alleviated by the use of antidepressants. Therefore, a ME/CFS patient misdiagnosed as being primarily depressed may not receive disability.

4. This difficulty may be eliminated by a physician's statement that any depression is clearly secondary and dependent on the patient's physical illness (CFS). In some cases, letters from psychiatrists to this effect have actually enhanced a claimant's disability application.

5. However, according to Attorney Kansky, there are important reasons not to, unless absolutely necessary, introduce or develop a diagnosis of depression or mental impairment into a CFS disability application, even one of secondary depression.

6. The first reason is as follows: **under most private, employer-related disability policies**, there is a provision for completely terminating benefits after two years (for those under 65) if there is a finding that depression contributes to the individual's disability. Any such attempt to terminate benefits on these grounds may be challenged by means of a physician's report stating if ever, in the future, the patient were relieved of all his/her physical symptoms, then there would be no primary or secondary depression that would prohibit the claimant's return to gainful employment activity - in other words, the depression would not contribute to any continuing disability. Introducing a diagnosis of depression can jeopardize the long-term financial interest of anyone receiving, or in a position to receive, long-term disability benefits. Such diagnoses should clearly be avoided in a Social Security disability claim of a person receiving employer disability benefits (or for a person who potentially might receive such benefits). Note: as of 2021, some insurance companies had previously introduced new policies for "subjective" illnesses such as ME/CFS with maximum benefits of two years only. In an individual case under such a policy, the mental impairment issue just discussed may not be at issue since the policy is for two years only.

Disability attorneys should fight any notion that ME/CFS is a "subjective illness" and introduce, for instance the 2015 U.S. Institute of Medicine Report which concludes the illness is objective and organic. Also the 2014 Social Security Ruling is an excellent document for this purpose.

7. The second reason to avoid mental impairment and depressive diagnoses (even a diagnosis of secondary depression) in a Social Security application and record is the potential for possible stigmatization. The diagnoses become part of a permanent government record; if an effective therapy for ME/CFS is found or if a patient goes into remission so that he may again work, the tag of depression or mental impairment may become an obstacle to future job and other opportunities. Social Security records are not entirely inaccessible.

8. Attorney Kansky believes that, in most cases of ME/CFS, use of the mental impairment or depressive diagnosis is not required to obtain a favorable disability finding. ME/CFS has up to 10 or 20 disabling symptoms which taken either by themselves or in combination are more than sufficient to prevent employment. Mental impairment diagnoses are not required in the presence of so many physical symptoms of such severity. An attorney who has sufficiently researched the illness and has familiarized him/herself with the client's physical symptoms and their disabling effect can assist a physician in preparing the medical report without introducing the depressive diagnosis.

9. Attorney Kansky tries to avoid introduction of these diagnoses, since he believes they are generally not necessary and could be a serious problem for the claimant in the future. To date, he has not found it necessary to introduce these diagnoses in order to obtain favorable decisions.

How to resolve the two different points of view above. An individual should listen to a prospective attorney's view of the issue, if it comes up. Then the individual will have to assess the attorney's opinion. The Mass. ME/CFS&FM Association can recommend experienced attorneys.