

**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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*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 VIII

### Disability Case Reviews

Once you have been approved for Social Security Disability (SSDI and SSI) and are receiving benefits, Social Security, periodically, will conduct a review of your case in order to re-determine your eligibility for benefits.

The purpose of the review is to determine whether the individual remains totally disabled; that is, the individual is still unable to do any work, even part-time sedentary work on any predictable basis.

If Social Security finds the individual is no longer disabled the benefits will be discontinued.

The new 2014 Social Security Ruling on ME/CFS requires the same specific documentation for reviews as it does for an application. Please review carefully the section of this booklet which explains the Ruling.

During a review, you will have to establish that you have a medically-determinable impairment – CFS. Your doctor will have to document the required medical signs and laboratory tests – or “other findings which are consistent with medically-accepted clinical practice and is consistent with other evidence in the clinical record.” Again, the required documentation should include a longitudinal clinical record of at least 12 months prior to the date of the review. Because a review can come at any time, a PWC should maintain a continuing relationship with a doctor, who, at least at 3 to 6 month intervals, should note medical signs in the record and take periodic lab tests. Of course, if a review can be anticipated, the patient should improve the frequency of entries in the clinical record during the 12 months prior to the review.

The doctor’s medical report must also document the individual’s inability to work. This documentation should also be noted periodically in the clinical record. Please see other portions of this booklet including “Documenting the claimant’s inability to work.” Also, as noted in the Ruling in the section, “Letters Supporting the Disability Claim”, you should submit appropriate letters from other persons.

When a review begins, you will receive a letter announcing the review. Although the letter may not state that you are required to take any action at this stage of the review, once you receive the letter (if you are still disabled) you should immediately contact your physician(s) in order to obtain a current medical report/physician's letter.

(Sometimes, a person will receive a “pre-review questionnaire” containing a few simple questions. This purpose of this form is simply to determine, by the answers to the questions, whether the person should be reviewed. For instance, if the person answers that they are

improved, or that their doctor says they can work, then a review may be undertaken. If you receive such a form, answer the questions carefully and make sure they reflect the ongoing severity of your disability. If you have any questions, call the disability committee through “contact us” at the Massachusetts ME/CFS & FM Assn website. Also, if you are in any doubt that a review has actually begun, you should call Social Security and ask. If a review has begun, you must act.)

The physician’s letter/report should comprehensively document the following:

1. Your continuing diagnosis(es). Your doctor(s) should document, in detail, the chronicity and severity of your major symptoms and should provide a full assessment and prognosis of the continuing severity and chronicity of your disabling illness(es). The doctor should also report on any failure of improvement and treatment since the award of benefits.
2. Your doctor should document how the continuing seriousness of your illness and symptoms totally disable you from working. He/she should also document how your illness severely limits your ability to function in the primary areas of your life: personal care, household duties, family life, social life, etc.

The same general instructions apply for the type of documentation to be included in doctors' letters for reviews as apply for medical reports submitted in the various application stages. Therefore, for more detailed information on the type of documentation and language to be included in review letters, see Appendices I and IV. Also for Fibromyalgia, Appendix III.

You should maintain a continuing relationship with your physician(s) and providers so that you will be in a position to timely document your disability during a review. Urge your doctor to prepare your report as soon as possible. If you can, obtain a copy of the report and submit it to Social Security as quickly as possible. If not, try to make sure your doctor submits the report as soon as possible.

It is of utmost importance that Social Security obtain the letters/reports before the agency makes an initial decision on your review. Often individuals are initially found not to be disabled because the state agency does not receive the medical documentation quickly enough. It is much better to get re-approved immediately rather than having to go through appeal stages -- even though you are likely to be re-approved at a later stage if you can provide the necessary documentation.

Find out from your case manager at Social Security the date by which your submissions should be in. If you need a little more time, call the representative and ask for a reasonable extension.

If, after the initial review, you are told that you have been found not to be disabled, you should appeal immediately in writing for reconsideration. You may have all your benefits continued until a decision on reconsideration, but only if you specifically request in writing that your benefits be continued and only if you do so within 10 days of the initial rejection decision. (You

have 60 days to file for reconsideration, but if you want your benefits continued, you must act within 10 days.)

During reconsideration you may be asked to attend a face-to-face hearing with the person reconsidering your case to explain why you feel you are still disabled and to submit any further documentation of your disability. If you did not provide the necessary documentation at the initial review stage, be sure to obtain and submit the documentation at this time. Although you may be told the reconsideration hearing is informal, it is in fact a serious and legal hearing -- it is possible to make a mistake at this hearing that your attorney will not be able to correct at a later stage. Therefore, individuals are advised not to attend reconsideration hearings without representation by an experienced disability advocate or attorney.

Very often disability benefits will be reinstated at the reconsideration stage. If you are again turned down, you should immediately appeal for a hearing before an administrative law judge. This appeal hearing is similar in nature to the appeal hearing that occurs during the application process. Please see Appendix IV for advice on necessary hearing preparation. You should definitely have an experienced attorney or advocate represent you at the hearing.

If you are turned down at reconsideration after you have been afforded an opportunity for a face-to-face hearing, your benefits will be discontinued. If this happens, you should file an appeal for an Appeal Hearing. If you win, your benefits will be restored. If you requested that your benefits be continued through reconsideration and you do not win after further appeals, you are generally required to repay the benefits you received following the initial rejection. However, you may apply for a waiver so that you will not have to repay. The waiver may be granted if you can convince Social Security that you asked that your benefits be continued in good faith - that you believed that you continued to be disabled. Moreover, Social Security can take ability to pay into account in seeking repayment.

Frequency of reviews:

When you are accepted for disability your certificate of award tells you when you can expect your first review. Generally, how often your case is reviewed depends on likelihood of improvement and severity of your condition. The following are social security guidelines on the timing of reviews:

Improvement expected: If improvement can be predicted when benefits begin, the first review will occur in 6-18 months.

Improvement possible: If medical improvement is not predicted but is possible, review about every 3 years.

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Improvement not expected: If medical improvement is not likely, review will happen every 5-7 years.