

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

**Kenneth S. Casanova**  
*Massachusetts CFIDS/ME & FM Association*  
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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

## APPENDIX III

### How to Prepare for an Administrative Law Judge Hearing (3rd stage)

*Note:* The following material reflects the actual experience of a disability lawyer in relation to a CFS Administrative Law Judge Hearings. Other attorneys with CFS hearing experience might have differing suggestions or opinions from those contained in these memos. For instance, one attorney who has done CFS hearings does not believe that submitting a report by a vocational rehabilitation specialist is vital to winning a hearing.

However, these memos do contain valuable suggestions. The first memo in this series is the most recent, therefore its specific suggestions for preparing medical reports or patient exhibits should take precedence over similar suggestions in the earlier memos.

### Specific Suggestions on Preparing for the Social Security Hearing From Disability Lawyers

1. The patient should seek from his or her physician an updated medical report. The updated medical report should indicate which medical/lab tests were positive and also, if truthful, and if your doctor is willing, please have him or her summarize your condition in his report in the following way:

In my opinion, to a reasonable medical certainty, (*name of patient*), by reason of unpredictability of the frequency and severity of his or her multiple physical symptoms of CFIDS, is unable to engage in any substantial, competitive, gainful employment activity, even light part-time sedentary work from his or her own home. By reason thereof, he or she is totally disabled. Based upon the history provided and records in my possession, it is my further opinion that he/she has been so totally disabled since (*date*) and [*if applies: given that he/she has been so totally disabled for 12 consecutive months or more and will remain so totally disabled for the foreseeable future*], but in any event for not less than the next 12 consecutive months and therefore, his/her total disability must be deemed permanent. His/her prognosis remains guarded.

Furthermore, it is recommended that, if the patient suffers from no separate diagnosis of primary depression or no significant secondary depression related to the CFIDS, that the doctor also include, if willing, the following paragraph in the updated medical report:

Finally it is my opinion to a reasonable medical certainty, that (*name of patient*) suffers from no depression or other mental or nervous condition which in any way contributes to his/her total disability.

2. It is also recommended that at the time the patient applies for the hearing, he/she begin to prepare the following exhibits, to be submitted to the judge approximately one month prior to the hearing date. In preparing these exhibits, as well as the pertinent hearing forms, the patient should collaborate in

their preparation with a friend who also would be the person driving the patient to and from the hearing. The purpose of this collaboration is for the judge to understand that the patient needed help in preparing the forms and the exhibits; otherwise the judge might speculate that the patient was capable of doing some work. Each exhibit should be prepared on separate pages, and all exhibits should end with the following phrase:

Signed under the pains and penalties of perjury this (*day, month, year*)

*Also at the end of each exhibit include the following wording:*

I was assisted in the preparation of this exhibit by: (name, address).

**List of Exhibits the claimant should prepare:**

- a) Fill out the *CFIDS Symptom Checklist*. Please complete, date and sign the list after checking symptoms. In filling out the form, you should include all important recurring symptoms produced by your illness. Generally these will be symptoms that have lasted or recurred throughout your illness. (see Appendix II for checklist)
- b) *Claimant's Medications* -- complete, date and sign.
- c) *Typical day in the life of (name)* from 8:00 A.M. one day to 7:59 A.M. the next day, in outline form on an hour-to- hour basis.
- d) *Examples of episodes which highlight my cognitive dysfunction*. List some of the major examples of cognitive dysfunction which do not involve operation of a motor vehicle -- approximately 7-10 examples will be sufficient, also signed under the pains and penalties of perjury at the end.
- e) *Why I am unable to do light part-time sedentary work from my home*. List the reasons why you are unable to perform:
  - Word-processing and typing from your home;
  - telemarketing from your home;
  - stuffing envelopes;
  - companion to the elderly;
  - and child care from own home. Again, at the end, sign under the pains and penalties of perjury and date.
- f) *List of activities formerly enjoyed*:. Prepare a list of activities formerly enjoyed by you, which you are no longer able to do by reason of your total and permanent disability from CFIDS. Likewise at the end, please sign under the pains and penalties of perjury and date.
- g) If you have no separate diagnosis of primary depression, nor any significant ongoing secondary depression already documented by your physicians, also prepare the following exhibit:

*Why I am Not Depressed*: Prepare on separate sheet or sheets of paper, a separate exhibit listing all of the reasons why you believe that you do not suffer any depression or mental or nervous condition

which contributes to your total disability, likewise signed at the end, under the pains and penalties of perjury. **(Note: Please see Appendix IV for a discussion of the issues and problems, and pros and cons, of introducing a diagnosis of depression or mental impairment into a CFS disability application.)**

## **Necessary Elements in Preparation for Social Security Appeal Hearing of a CFS Disability Case**

The following is based on the experience and practice of disability attorneys who have obtained a number of successful decisions for clients with CFS from administrative law judges (ALJs),

1. At least several weeks prior to claimant's hearing the attorney should obtain a copy of the claimant's record from Social Security. The attorney, after reviewing the record, can note the need for either clarification or correction of material already in the record, or for additional documentation to further strengthen the claimant's case.
2. When clarification or correction of material in the record is necessary, the attorney may contact the physician or other providers to see if he or she is able, truthfully, to provide, in written form, such correction or clarification.
3. In all cases, after examining the file and prior to the hearing, the attorney may send to the physician a sample letter which contains, generally, the type of language which is necessary to strongly document a CFS diagnosis and a CFS claimant's inability to work. The purpose of sending this sample letter is to solicit from the physician the best possible letter, which is truthful, on the claimant's current condition. Included with the sample letter is a letter from the attorney, asking the physician, if he or she believes the letter to be truthful and applies to the claimant, to use the sample letter and its "buzzwords" as the basis of the physician's updated letter.
4. The two key phrases, in the updated medical report, that judges would like to see are as follows:
  - a) the client is "unable to engage in any gainful employment activity, even light, sedentary work, part-time."
  - b) the client "likely will be unable to perform any such work for the next 12 successive months."

The physician should include a copy of his curriculum vitae with the updated medical report.

5. The attorney should screen all reports, medical and otherwise, before such reports are forwarded (by the attorney) to Social Security or the ALJ. By so doing, any matter or language requiring clarification or correction can be discussed by the attorney with the provider. (Necessary changes in letters can be made before the letter is submitted.) Normally, if possible, the doctor will provide the claimant with the report, which the claimant will then give to the attorney. (This process also allows the attorney and client to cross-check necessary information.)
6. Prior to the hearing a vocational expert who has an understanding of CFS could test the claimant to determine his or her level of ability and stamina. As part of the testing process, the expert should

arrange for the claimant to call several days after the conclusion of the testing to report the after-effects on the claimant's health resulting from the testing process. Often, following the rigors of testing, the claimant will be bedridden for several days. If this occurs, a notation to this effect in the vocational report is very useful.

An already prepared vocational report to be submitted for the hearing is an important asset since the judge may then decide that a report from his own vocational expert (who may not be familiar with CFS) is unnecessary.

7. Ask the client to prepare, sign, and date, in handwriting, the following four documents:

- a) A typical "day-in-the-life-of" description of the effects of the illness on daily activity;
- b) A list of the medications taken;
- c) A few events from the past year to a year and a half that highlight the claimant's cognitive dysfunction (but not involving the operation of a motor vehicle);
- d) Why the client cannot even do telemarketing from his or her home. (This is a very good question for a CFS patient since it shows the inability to maintain a schedule, i.e., the unpredictability of the illness. It also demonstrates the problem of cognitive dysfunction: the inability to maintain records; it may also show how the symptoms of sore throat and upper respiratory infection make talking difficult.

8. The client should be driven to the hearing by a person who can testify for the claimant.

9. The client should obtain an attorney who will be compassionate, thorough, and cooperative, and who understands and emphasizes the *unpredictability of the frequency and severity of symptoms* of the illness. The key point to be emphasized is the unpredictability of the illness, and therefore the patient's inability to plan.

## **Further Suggestions**

The claimant might consider any one or more of the following supplements:

1. Maximize the relationship between the severity of the symptomatology and how it renders the claimant totally disabled.
2. Whenever a claimant appears before an Administrative Law Judge, it is a good idea to have them driven there by a friend or family member - this helps reinforce the dependency upon others for such matters as grocery shopping, routine short-term travel, and most important of all, the key buzzword - "unpredictability" of onset of symptoms - if the Judge asks, "How did you get here today?"
3. In their appearance before the Administrative Law Judge, it is advisable for the claimant to have prepared in advance a *list* of their most frequent daily symptoms, how each symptom disables them,

the usual extent to which it disables them, and most important, how any one or more of the symptoms can come upon them with little, if any, advance notice (resulting in the unpredictability factor, which renders claimants unable to maintain any viable work schedule, with any degree of regularity).

4. From a list prepared in advance, it is recommended the claimant give a brief synopsis of a "typical day in the life of" the claimant." The use and need for notes to do this helps emphasize the short-term memory loss and cognitive dysfunctions from which claimants suffer.

5. It is preferred that if possible they keep their emotions partially, but not entirely, in check, to the extent they are able. If they are answering a question which to them is an emotional trigger, claimant should try to retain composure even if it takes an extra moment or so -- take a deep breath and relax -- and counsel should temporarily, if able, switch claimant onto a less emotional area of his/her disability, to help them regain composure and then field the question in a short while. This effort is usually appreciated and respected by the Administrative Law Judge.

6. Claimants should dress casually and comfortably wearing the same type of clothing they would wear around the house if, by way of example, guests were coming to visit them a few days after they have returned home from the hospital after a minor surgical procedure -- loose pullovers, sweat pants, sneakers, etc., are fine as long as neat and clean. Claimant can even explain why generally they wear this style of attire -- because of the reduced effort it takes to dress themselves on those days when they are able to get up and out of bed.

7. The key to any of the reports is to have an evaluating physician review all past reports, tests, and records, and detail briefly for the patient what symptoms cause them the most difficulty and how the unpredictable nature of the severity and frequency of the symptoms does render them unable to engage in any light, adjusted or sedentary work, never being able to reliably appear for work most days either punctually or at all.

8. When filling out a Request For Consideration form, it is highly recommended that the claimant indicate that he will be producing new and additional evidence and that (if truthful) his symptoms have, become more severe and more frequent, i.e., to show a condition which is a progressive disabling condition.

9. An Administrative Law Judge might ask a claimant if he could walk two blocks -- and the answer may be truthfully yes -BUT it is up to the claimant to add that if he does, he will end up being bedridden for the next 4 days (as an example). Many CFS patients can perform lengthy tests conducted in offices of psychologists, physicians, vocational counselors, and physical therapists and, of course, the reports of these professionals to Social Security would be that the tests were performed by the claimant successfully. Then it becomes up to the claimant and his representative to indicate to the Administrative Law Judge the after-effects of these physically and possibly emotionally strenuous tests.

10. De-emphasize the depression aspects of the illness in that that could be a stigma. Once made part of the record, it is very difficult to overcome, unless of course we are referring to a secondary depression resulting from the experience of having to undergo such a major change in lifestyle and ability.



11. A special effort should be made not to overwhelm either his/her representative or the Administrative Law Judge with a plethora of material or a day-to-day diary for the past two or more years. First, anyone capable of writing and producing so much material could probably get light work proofreading or writing short stories at home -- or at least it would appear that way to a vocational expert or Administrative Law Judge. Second, neither the claimant's representative nor the Administrative Law Judge needs to know everything that might be contained in a plethora of material that could qualify as an autobiography. A competent representative can advise a claimant as to what information is being sought by the Administrative Law Judge by which he can render a favorable ruling expeditiously if he so finds. Too much material will only confuse and cloud the really few key issues that the Administrative Law Judge must have addressed in order to render a fair and hopefully favorable decision.

12. The claimant and his representative should make arrangements to obtain a copy of the "record." on file at the office of Hearings and Appeals where the Administrative Law Judge presides at least a couple of weeks in advance so that if there is a clear error of fact (more than just an adverse opinion) it can be brought to the attention of the health care professional who prepared the report. If there are one or more adverse opinions in the record by health care professionals, then a more updated report by another health care professional, i.e., claimant's attending physician or evaluating physician can explain in his later, more current report, perhaps based upon certain updated research and findings, why the claimant is disabled -- i.e., to refute the prior adverse opinion indirectly, but effectively.

13. It is recommended that wherever and whenever possible, the health care provider, i.e. a practicing non-holistic M.D., indicate in the report that the prognosis is guarded, that the claimant has been or is likely to be permanently and totally disabled from engaging in any substantial gainful employment activity now and in the foreseeable future (to total no less than 12 months, separately or in combination) and that there is at present no known cure, treatment, or management program for this disease which would allow the claimant to return to any, even light or sedentary gainful employment activity in the foreseeable future. This applies even to those claimants whose work is not physical, but whose thought processes are adversely affected by short-term memory loss and cognitive dysfunction.