

**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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## **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 IV

### Helping Your Doctor Document Your Illness and Disability to Social Security (and to other Disability Carriers)

This Appendix includes the following:

**1. Memo from Bernard A. Kansky, Esq.: Recommended Documentation of CFS Disability to be submitted to Social Security and/or for Private or Employer Disability.** Based on Attorney Kansky's extensive experience adjudicating ME/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.

**2. The ME/CFS Symptoms Checklist.** A comprehensive listing of ME/CFS symptoms. You and your doctor can use this listing to document your symptoms and as a submission to Social Security and other disability carriers.

**3. Some Tests to be Conducted to Help Determine Objectivity of CFS, and/or Disabling Symptoms.** Compiled by Dr Charles Lapp. In addition to the tests contained in the CFS Criteria (Appendix 1) and those suggested by Dr. Komaroff (see section on physicians' letters in the booklet proper), these tests are designed to provide Social Security and other disability carriers with objective evidence of CFS.

**4. Excerpts from previous Social Security CFS Documents:** *These excerpts, when not in conflict with the new Social Security CFS Ruling, may be useful in elaborating the Ruling – especially when applicants must use medical signs, symptoms and lab tests not specifically listed in the new Ruling.*

#### A. Excerpts from "Documentation for the Social Security Administration's

Adjudication of Disability Claims Involving Chronic Fatigue Syndrome (1997)"

This 1997 Memo from the Associate Commissioner for Disability provides: (1) details of how Social Security evaluates a disability claim, (2) detailed documentation which physicians should include in their medical reports. **Give a photocopy of this Memo to your Doctor.** (3) Suggested documentation from non-medical sources.

5. **Incapacity Checklist:** This checklist can help in evaluating your inability to work. You may give a copy of this checklist to your doctor to assist him/her in preparing your medical report.

6. **Sample Doctors' Letters** written to Social Security to document ME/CFS patients' disability claims. *Please read the instructions carefully on how to use these letters.*

7. A section on: **Helping Your Doctor Prepare Your Medical Report.** This section provides suggestions on how you can work with your doctor to help *him/her prepare* the best possible medical report.

**Memo from Bernard A. Kansky, Esq.:**  
**Recommended Documentation of CFS Disability Claim to be Submitted to Social Security and/or for Private/Employer Disability**

*You can make copies of this Memo and give one to each provider who will make a medical report supporting your claim.*

When applying for Social Security Disability Benefits and/or Private Long Term Disability Benefits, consider the following:

1. Mass. ME/CFS Symptom Check List with any reference to psychological disorder or problems being unanswered or deemed not applicable if relief of all physical symptoms would allow return to full-time gainful employment activity.

(Note: Cognitive dysfunction caused by ME/CFS is not a psychological disorder. See section on cognitive dysfunction.) For more information on issues of psychological disorder in a ME/CFS disability claim, see Appendix VI and the supplementary diagnostic material section in the main body of the booklet).

2. Results of a comprehensive vocational test by a vocational expert thoroughly familiar with ME/CFS who is well respected by colleagues and Administrative Law Judges alike. This should be a detailed narrative report describing the extent, by degree, of the patient's ability or inability to perform in a simulated work environment. **[Submission of this type of report is entirely optional.]**

3. Detailed narrative reports by primary care physician familiar with ME/CFS, an ME/CFS specialist, and all other health care providers which include:

(a) The medical history.

(b) A schedule of all lab and other *objective* tests for which there were positive findings along with the numerical results of those *objective* findings.

(c) An indication of *regular* visits, and the frequency thereof. (If the claimant is totally

disabled, both Social Security and the Long Term Disability Carrier expect the Claimant to maintain regular medical visits).

(d) The physician's notations of the complaints and subjective symptoms along with notations of any unsuccessful attempts to return to work, if any such attempts were or could be made.

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The following are observations by Attorney Kansky regarding back-to-work attempts by disability applicants:

After resting at home for a period of time, some claimants believe they are well enough to attempt a return to full-time or part-time work. Before actually attempting a return to any work, many claimants will self-test their stamina and ability to maintain a schedule by going to the local library, 2 days a week, 8:30 a.m. to 1:00p.m., gradually increasing the number of days per week, and then gradually increasing the number of hours per day, i.e., from 8:30a.m. to 1:00p.m., and from 2:00p.m. to 4:30p.m.

Experience has shown that those persons suffering Chronic Fatigue Syndrome who attempt a return to work, before they are well enough to do so, suffer severe exacerbation of symptoms and run the very real risk of being discharged for non-performance or poor performance and poor attendance, placing all of their employee benefits at risk.

In addition, many now believe that a partially successful or unsuccessful attempt to return to work, even light duty, part-time, sedentary work. may be misconstrued by Social Security and/or private long term disability benefit carriers who do not understand CFS, thereby jeopardizing those benefits as well.

Based upon the unfortunate experiences of others, many claimants now concentrate their efforts on obtaining the benefits to which they are lawfully entitled, and thereafter, when desirous of attempting a return to work follow the rules and regulations prescribed for such an attempt by Social Security and/or their LTD carrier.

(e) The diagnoses of ME/CFS in combination with any other diseases which Claimant may have.

(f) The detailed history of the various treatments attempted. Describe those treatments which minimized symptoms: describe those which did not work; those which were intolerable to Claimant and what adverse impact, reaction or exacerbation was suffered by the Claimant from each and all such treatments.

(g) Prognosis, which for ME/CFS is at present, uncertain and guarded.

(h) The medical opinion, if truthful and correct, to the effect that the patient has been totally and permanently disabled by reason of the unpredictability of the frequency and severity of his/her multiple physical symptoms since the date of onset, and for not less than

twelve consecutive months; and in any event, for the foreseeable future in that at present, there is no known treatment, cure or management program for this disease. The Claimant is unable to engage in, and more importantly, sustain, any gainful employment activity, even light part-time, sedentary work from home.

(If the language in this item truthfully applies to the claimant, **it is suggested that the physician directly incorporate the language into his/her Report.**)

(i) If truthful and correct, include the opinion of the physician that the Claimant suffers no mental disorder, nervous disorder, psychiatric or psychological disorder which contributes to his permanent and total disability. If, as, and when, a cure, treatment or management program for this disease is discovered, and the Claimant is relieved of all of his physical symptoms, then there should be no disorder which would prohibit him from returning to gainful employment activity.

### ***Checklist of ME/CFS Symptoms***

Regarding the following two checklists of symptoms and tests: Given the new CFS Ruling's emphasis on frequent documentation of signs and symptoms by the physician, it would be reasonable for the patient/applicant to review the two lists with his/her doctor during each office visit and to enter the positive findings into the physician's chart.

***(Percentage following symptom is percent of ME/CFS patients experiencing symptom)***

#### **1. Most common symptoms**

- Fatigue (100%) (*exhaustion, usually made worse by physical exercise*)
- Low-grade fever (60-95%)
- Recurrent flu-like illness (75%)
- Painful lymph nodes (30-40%) (*especially on sides of the neck and under arms*)
- Joint and muscle pain (65%)
- Post-exertional malaise - PEM (50-60%) (*a feeling of debility, discomfort or lack of health similar to that experienced at the onset of an illness*) **Note: Since this list was compiled, PEM is now considered a primary symptom of the illness.**
- Symptoms worsened by extremes in temperature
- Multiple sensitivities to medicines, foods, and other substances
- Severe nasal and other allergies (40%) (*often a worsening of previous mild problems*)
- Weight gain / weight loss
- Severe muscle weakness (40- 70%)
- Stiffness (50-60%)

#### **2. Psychological symptoms**

- Depression (70-85%) (*reactive or secondary depression*)
- Anxiety (50- 75%) (*including panic attacks and personality changes*)
- Emotional lability (mood swings)
- Psychosis (1%)

### **3. Other nervous system symptoms**

- Impaired cognition (50-85%)
- Attention deficit disorder
- Calculation difficulties
- Memory disturbance
- Spatial disorientation
- Frequently saying the wrong word
- Sleep disorders (15-90%)
- Frequent unusual nightmares
- Night sweats (30-40%)
- Nocturia (50-60%) (*excessive urination during the night*)
- Nonrestorative sleep
- Headaches (35-85%)
- Dizziness (30-50%)
- Visual blurring (50-60%)
- Numbness or tingling feelings
- Disequilibrium (*feeling off-balance or dizzy*)
- Light headedness (*feeling "spaced out"*)
- Difficulty moving your tongue to speak
- Ringing in the ears
- Intolerance of bright lights
- Difficulty moving your tongue to speak
- Ringing in the ears
- Intolerance of bright lights
- Intolerance of alcohol
- Alteration of taste, smell, hearing
- Twitching muscles (*"benign fasciculations"*)

### **4. Other symptoms:**

- Pharyngitis (50- 75%) (*inflammation and discomfort of the pharynx*)
- Dyspnea on exertion (*labored breathing or hunger for air*)
- Worsening of premenstrual symptoms (70% of women)
- Tachycardia (40-50%) (*abnormal; rapid heart action*)
- Chest pain
- Nausea (50-60%)
- Parathesias (30-50%) (*abnormal sensation of tingling or discomfort at odd intervals*)
- Diarrhea, intestinal gas or irritable bowel (50%)
- Dry eyes (30-40%)
- Dry mouth (30-40%)



- Anorexia (30-40%)
- Hair loss
- Cough (30-40%)
- Finger swelling (30-40%)
- Cold hands and feet
- Rash (30-40%)
- Herpes simplex or shingles (20%)
- Frequent canker sores

**5. Less Common Symptoms:**

- Mitral valve prolapse
- Paralysis
- Seizures
- Blackouts
- Sciatica
- Thyroid inflammation
- Periodontal disease
- Endometriosis

The above statistics were compiled from data by Paul R. Cheney, MD, Ph.D" Jay A. Goldstein, MD, Anthony L., Komaroff, MD, and Daniel Peterson, MD.

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**Some Tests to be Conducted to Help Determine Objectivity of and/or Disabling ME/CFS Symptoms**

1. Low blood pressure
2. Tender/palpable lymph glands
3. Allodynia (sore or tender skin)
4. Tender trigger points
5. One pupil larger than the other
6. Coated tongue (candida) and other skin conditions
7. Rosacea (a skin condition where blood vessels grow close to skin a/k/a butterfly rash)
8. Acne-resistant to usual treatment
9. Lesions on the body (red & crust - come and go)
10. Shingles
11. Atrophy of fingers ("furrows" which can obscure a fingerprint)
12. Swelling of the lymphatic system, especially in the nodes along clavicle, frequently left

side clavicle

13. Thoracic duct tender

14. Check for clonus

15. Signs of Romberg

16. Crimson crescents to the sides of uvula

17. Check for low-grade fever

18. Brain scan

*Source: Partial listing of tests and objective findings by Dr. Charles Lapp, Cheney Clinic, Charlotte, NC.*

#### EXCERPTS FROM OLDER CFS SOCIAL SECURITY DOCUMENTS

Here are a few excerpts from older Social Security documents on CFS that provide a few extra guidelines that should be kept in mind in terms of physician documentation of the ME/CFS disability.

#### **Medical History**

The medical history should discuss in detail the complaint(s) alleged as the reason for disability. The history should include:

- A complete description of the problem(s);
- How long the problem(s) has {have) been present;
- If the condition is episodic in character or tends to exacerbate and remit over time; [If this is the case, the dates of episodes, known precipitating factors, and the state of health and ability to function of the patient between episodes should be provided.]
- Any known factors that worsen the condition or that alleviate it;
- Any prescribed treatment (including medication(s) listed by name and dosage), response to treatment, compliance with treatment, side-effects of treatment; and

Laboratory Test Reports:

Should provide actual values for laboratory tests and normal ranges of values;

Interpretation of laboratory tests should take into account and be correlated with the history and physical examination findings.

**Information About Function:** Statements/opinions from the treating source(s) about the

impact of the individual's impairment on his/her ability to function in day-to-day activities of living are of great value to SSA in making its determination as to whether or not the individual is disabled. In this regard, any information the treatment source is able to provide contrasting the patient's medical condition and functional capacities since the onset of CFS with the patient's status prior to CFS is meaningful to SSA's evaluation.

SSA is also interested in information regarding how long the impairment(s) might be expected to limit the claimant's ability to function, the effects of any treatment(s), including side effects, and precise observations regarding how well the claimant is presently able to function. A simple statement by the physician that the individual is or is not disabled is not helpful since that is a decision that SSA must make in accordance law and regulations based on the medical and other evidence it has received.

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## **Incapacity Checklist**

The following Incapacity Checklist is taken from *How to Secure and Protect Your Social Security Disability Benefits*, published by the Mass. Disability Law Center.

This checklist can assist your doctor in evaluating your inability to work. You can give a copy of this checklist to your doctor along with the other memos included in this appendix.

*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
- other physical or psychological functional restrictions, and
- your ability to adjust to the stress of a work environment

## **Sample Doctors' Letters**

This section includes a selection of sample doctor's letters that were actually written to

Social Security to document patients' ME/CFS disability claims. These letters – Disability Reports -- are provided to help show how a doctor's letter should be written and the type of information it should contain in order to make the letter strong and effective.

These letters, though somewhat outdated by the new Ruling, may still offer a partial content and framework for a medical report – as long as, when possible, they are supplemented with the additional documentation listed in the Ruling.

Please read the explanations of each letter carefully, since although two of the letters are relatively strong, *each of the two letters lacks certain important information*. By studying each letter and the letter's instructions, you will know the strengths and weaknesses of each, thereby giving you and your doctor a good idea of what a model letter should contain. For purposes of comparison, the selection also includes the type of weak letter (which all too often is the type of letter submitted) that would **not** be effective in securing disability benefits.

A number of patients, having learned the basics of the content of the Disability letter, have drafted their own version of a letter that a physician could use in drafting his/her own Disability Report. Some doctors consider this helpful.

Note: These sample letters should only be used as a supplement to the other instructive material in this booklet. Attorney Kansky's memo in this Appendix is the best guide for doctors in preparing the medical letter. Just as important is the more recent document: Providing Medical Evidence for Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome ME/CFS” This Memo is a Guide for Health Professionals for providing medical documentation in support of a disability claim. It can be found and printed-out at: <https://www.ssa.gov/disability/professionals/documents/64-063.pdf>

### Explanation to Letter #1

Letter #1 provides a general framework or outline for documenting diagnosis (signs, symptoms, lab tests) and the inability to work. However, under the new CFS Ruling, the doctor should specifically document the signs/symptoms and lab tests listed in the Ruling as well as those consistent with CFS that are not listed. The physician should also explain how this documentation was obtained over the previous 12 month period. Clinical office notes can be appended to the letter.

Letter # 1 is a good example of the type of letter that would be effective in establishing a CFS patient's eligibility for Social Security disability. It adequately documents the patient's CFS diagnosis by providing the necessary detailed review of symptoms and symptom history. The letter also states that the patient's depression is a *result* of the ME/CFS rather than the *cause* of

the ME/CFS symptoms.

The letter also provides the required assessment of the patient's inability to work and to perform various tasks and activities. The doctor's statement that the patient is 100% disabled and unable to work is especially strong. While this letter represents a good medical report, an even stronger report would provide more detail on the patient's inability to perform a variety of daily tasks; the letter should also include an evaluation of the patient's capacity for lifting, walking, sitting, and standing. The letter would also be stronger if it included the results of diagnostically relevant laboratory tests. With these suggested additions, Letter # 1 would be an excellent medical report.

Letter #1

***To Whom It May Concern:***

I am writing to you to reiterate my conclusion that ( \_\_\_\_\_ ) is suffering from a disabling illness and is 100% disabled. ( \_\_\_\_\_ ) suffers from Chronic Fatigue Syndrome. To reiterate, she has undergone extensive medical, immunologic and physical examinations. Further neuropsychological testing will take place next month with Dr.( \_\_\_\_\_ ). ( \_\_\_\_\_ ) has the characteristic symptoms of the syndrome, i.e., severely disabling fatigue, malaise, myalgias, lethargy, weakness, nausea, dizziness, low grade fever, joint pain, sore throats, swollen glands, headaches, mental confusion, memory loss and impaired ability to concentrate. Since my last letter, ( \_\_\_\_\_ ) has described intensification of problems with memory, concentration, headaches, generalized weakness and fatigue. She continues to be under considerable psychological distress that is greatly exacerbated by her tenuous financial situation. Secondary depression that is a result of her long-term illness is also worrisome. ( \_\_\_\_\_ ) is currently taking amitriptyline as a joint therapy for that as well as for her sleep disorder and myalgias.

At present, restricting activity is the only way to prevent exacerbation of CFS symptoms. ( \_\_\_\_\_ ) is 100% disabled. She is capable of only mild intermittent activity. Her ability to sustain any activity for even a few hours a day is unpredictable. Any prolonged activity (even sedentary) worsens her condition and can cause exacerbation of her symptoms. Therefore, her activities of daily living are markedly limited as is her ability to complete tasks. This illness has radically limited ( \_\_\_\_\_ )'s life. She has been unable to maintain work at any level and her social life is virtually nil.

( \_\_\_\_\_ )'s physical symptoms have exacerbated since my last letter to your office and this illness has proved to be emotionally devastating. She is 100% disabled at this

time. Work for her is totally out of the question.

I will continue to follow ( \_\_\_\_\_ ) to investigate therapies to counteract the devastating illness.

If I can be of any further help in support of her application for disability benefits. please do not hesitate to contact me.

Sincerely, ( \_\_\_\_\_ MD)

### *Explanation to Letter #2*

Letter #2 shows the type of weak letter that would not be very helpful in establishing a CFS patient's disability claim.

*Please note that Letter #2 is for the same patient as Letter #1 and was written by the same doctor.*

Letter #2 simply states the diagnosis, but it does not include the necessary diagnostic detail as does Letter #1. The letter is also weak because it only states that the patient is unable to work; the letter provides no documentation as to specific restrictions in the patient's capacity for activity or work. (Again, compare this with Letter #1.)

Letter #2 is often the type of letter submitted by a doctor who is very busy or who doesn't understand that more detail is necessary if the letter is to be effective.

You should explain to your doctor the type of detailed documentation that s/he should include in the letter -- by doing so you will help your doctor help you. Most doctors will be glad to know how to write a stronger and more effective letter. One suggestion is to ask your doctor to let you see his or her letter (and the Social Security questionnaire) before they are mailed 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.

### LETTER #2

*To Whom It May Concern: ( \_\_\_\_\_ ) is a patient under my care at the University of Massachusetts Medical Center. She is a 20 year-old female who for the past 2 1/2 years has had an illness characterized by marked fatigue, headaches, and extreme difficulty thinking and concentrating. In addition, she complained of enlarged left cervical lymph nodes and a sore throat. Laboratory studies show no other etiology for patient's illness. It appears that*

*the patient has the chronic mono-like illness or as it is now called the chronic fatigue syndrome. This is a diagnosis of exclusion. It is clear in my mind that the patient is disabled from this illness and unable to work. It is difficult to predict the course of the illness, but only 20% of patients spontaneously get better. However, with future therapies, the results may be brighter. At present, ( \_\_\_\_\_ ) is clearly disabled from her illness and is unable to work.*

Sincerely, ( \_\_\_\_\_ ), MD

### Explanation to Letter #3

Letter #3 is included for several important reasons. First, the letter documents a case of fibromyalgia disability and, therefore, should be helpful to those patients with fibromyalgia reading this booklet. This is an excellent sample medical report (except for the limitations described below) for showing how to document disabling cases of both fibromyalgia and ME/CFS.

The first paragraph of the letter documents a physician's diagnosis of the patient's disabling fibromyalgia. The physician's method of documenting the diagnosis is adequate but somewhat weak. Instead of directly detailing the patient's symptoms, the physician makes reference to the symptoms typical of fibromyalgia and then goes on to state that the patient's individual symptoms are in line with fibromyalgia symptomatology. Hence, the diagnosis is by extension from the general illness with little reference to either the severity or intensity of the individual's actual symptoms. The letter would definitely be strengthened by more documentation of the individual's actual symptoms, including the intensity, severity, and chronicity of the symptoms. The letter would also be strengthened by the inclusion of a summary history of the development of the illness and its severity.

A major reason for the inclusion of this letter is its listing of the patient's inability to perform specific daily activities. The extent of the patient's profound disability is completely and unmistakably documented by the extensive and almost overwhelming amount of detail, which, in its entirety, shows how disabled the patient actually is. With this type and amount of detail of the patient's limitations in performing specific daily activities, it's hard to imagine that Social Security would not understand that the patient is completely and totally disabled.

Certainly, many doctors would not be expected to provide the amount of detail regarding the patient's specific limitations that is provided in this letter. However, a letter which provided only half the details contained in this sample letter would constitute convincing documentation of the patient's disability. Additionally, one would reasonably assume that the patient provided the physician with the extensive list of her daily limitations. Disability applicants can assist their physicians with preparing medical reports by providing them with this type, if not quite so lengthy, listing of their inability to perform actual daily activities. Such a listing should fully and

comprehensively document the range of the patient's limitations, but should not be so long as to overwhelm the physician.

This sample letter is also valuable in its deliberate use of semi-legal language in documenting the extent and duration of the patient's total disability (see the last sentence of the letter's second to last paragraph and the final paragraph itself). The physician should be encouraged to include this type of language in his or her medical reports.

### Letter #3

RE: \_\_\_\_\_

DOB. \_\_\_\_\_

Dear Sir:

Ms. \_\_\_\_\_ has long-standing fibromyalgia, a disorder characterized by profound fatigue, generalized pain with involvement of the spine, upper and lower extremities, characteristic and diagnostic tender points, sleep disruption, nonrestorative sleep, and morning stiffness. A minority of such patients are disabled by incapacitating fatigue and myalgias aggravated by repetitive or sustained physical activities. Ms. \_\_\_\_\_ is one of these individuals. Her symptoms are consonant with her disease. She has obtained only modest improvement with the use of NSAIDs and amitriptyline.

Examination reveals tender points over the nuchal ridges. C7, trapezii, pectoral regions, supraspinatous origins. lateral elbows, glutei, trochanters and medial knees.

Ms. \_\_\_\_\_ has had marked impairment of her daily activities and finds it difficult to get out of bed, to dress herself, to get out of a bathtub, to wash her back and hair, to dry herself, to cut fingernails and toenails. to apply makeup, to walk up or down stairs, to get up and down a curve. She finds it impossible to walk up or down a slope. She has difficulty in cutting meat, opening bottles, pouring a cup of tea or coffee, opening jars, reaching above or below the counter-top, filling saucepans, carrying pans to the stove, removing hot dishes from the oven, draining vegetables, pouring hot water from kettles. She finds it impossible to peel or slice vegetables, grocery shop without assistance. She has difficulty in carrying a full cup and saucer or hot casserole. She has difficulty with scraping and stacking dishes, washing dishes, picking up objects from the floor, wiping up spills on the floor, sweeping the floor, using a dustpan, cleaning the refrigerator. She finds it impossible to scrub pots and pans, mop the floor, wash the floor or clean the oven. She has difficulty in hand-washing laundry or machine washing, laundering and folding sheets, as well as making beds, changing beds, using scissors, handling coins. She finds it impossible to wring laundry, hang laundry on the line, iron, dust, or



clean high and low surfaces, vacuum: clean out the bathtub. She has difficulty in getting in and out of a car and finds it impossible to get onto a bus or stand on the bus holding the over-head bar, or descend from a bus. She has difficulty in managing medicine bottles, holding a book, turning pages, winding a clock or watch, sweeping the porch, opening and closing windows, opening milk cartons, managing wall plugs, using a spray can, opening doors with keys. She is unable to write for fifteen minutes, shuffle and hold a hand of cards, care for her garden.

While an exercise program has been recommended and has been attempted, some individuals such as Ms. \_\_\_\_\_ experience intolerable pain even with minimal conditioning exercises; however, she has been encouraged to attempt to slowly increase her activities as permitted, but with little success. To date, I believe that her disorder is at a plateau.

By reason of the unpredictability of the frequency and severity of her multiple physical symptoms, Ms. \_\_\_\_\_ has been totally and permanently disabled from engaging in and, more importantly, in sustaining any gainful employment activity, even light part-time sedentary work at home.

It is my opinion that she is likely to remain disabled for the foreseeable future, but in any event, for not less than the next 12 consecutive months. Prognosis remains guarded and uncertain.

Sincerely yours,

M.D.

\_\_\_\_\_  
Date

#### EXPLANATION OF LETTER # 4

This model letter is excellent in that it covers both the necessary detail of diagnosis and the detail of functional incapacity. It also includes language pertinent both to fibromyalgia and ME/CFS.

(All of these letters may seem like overkill, but if, overtime, you might digest the ideal medical disability report; then you may be able to write a draft yourself for your own case, or at least give a copy of this letter to your doctor to be applied to you.)

To whom it may concern,

I am writing today to provide a comprehensive disability report regarding my patient: \_\_\_\_\_ who has applied for disability benefits. I first evaluated: \_\_\_\_\_, and have seen her on \_\_\_\_\_ occasions since.

Ms. \_\_\_\_\_ has seen a number of physicians and health care providers since the onset

of her various medical illnesses and conditions, but in some cases the concentration was on the current and most troubling issue. Therefore, at this time, I want to address all her issues in this letter in more depth and the manner in which they interact and compound one another.

Her condition has been steadily worsening since a viral infection in (month/year) that had made her previously manageable fibromyalgia much worse and her level of function decline. She presented with widespread stiffness and pain, post-exertional fatigue drastically out of proportion to the level of activity, poor unrefreshing sleep, recurrent headaches focused on the left side of her head and eye, sore throats, deep muscle pain, joint pain, cognitive issues, bladder inflammation, hypertension, irritable bowel syndrome, feelings of altered sensation in her hands and forearms. She also has obvious osteoarthritis in her hands.

Upon examination, she exhibited 18 of 18 tender points in accordance with the ACR criteria for fibromyalgia.

Hers clinical presentation fits the American College of Rheumatology's criteria for the diagnosis of fibromyalgia. She was referred to Dr. \_\_\_\_\_ who confirmed this diagnosis.

However, the rest of her symptoms, her decline in function and lower threshold for any activity raised suspicion of Myagic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), particularly after they all began after a viral infection in (month/year).

Infectious Disease Specialist, Dr. \_\_\_\_\_, took a lengthy history, performed a thorough exam and performed numerous work-ups including extensive blood work to rule out any other possible explanation of her profound fatigue and recurrent flu-like symptoms. Copies of all these tests have been submitted.

A brain MRI showed scattered punctate white spots in the white matter, abnormal and although non-specific, are often seen in patients with ME/CFS. She also had an abnormal sleep study, but no sleep apnea. Again, this is consistent with ME/CFS.

Her complaints of deep muscle pain approx. 36 hours after activity that would have been previously tolerated is also consistent with ME/CFS as are the recurrent sore throats, tender axillary lymph nodes, and headaches...which are much more severe than headaches she had prior to this viral infection and some days are disabling in themselves. Some days they are accompanied by nausea. She has some situational anxiety due to her inability to work and tenuous financial situation, but no mental disorders.

It is my opinion that the medical evidence shows Ms. \_\_\_\_\_ fits the 1994 case definition for CFS as well as the more recent Canadian ME/CFS diagnostic criteria including the characteristic ups and downs of this disorder coupled with her concurrent condition.

As a result, Ms. \_\_\_\_\_ cannot be relied upon to form any regular, predictable work.

Although Ms. \_\_\_\_\_ has had fibromyalgia for ten years prior to the viral infection in (date), she had been able to work albeit in a flexible workplace that allowed for time off when necessary for fibromyalgia flares. She had also been able to engage in a variety of hobbies and social activities.

The arthritis in her hands began in (year) ...but has become much more severe in (month/year)... and continues to worsen.

While she was able to manage his fibromyalgia for so many years...the addition of ME/CFS has greatly debilitated her and affected her activities of daily living. I have had her on trials of gabapentin and flexeril for the fibromyalgia, but she had to discontinue due to adverse reactions (itchiness from the gabapentin, grogginess and unsteadiness with flexeril). Ultram prescribed by the previous PCP (name) helped somewhat with the pain, but had to discontinue it due to a reactive allergy (dermatitis). Aspirin, non-steroid anti-inflammatories, and Celebrex are not effective. She tried physical therapy but had to discontinue because of post-exertional fatigue and loss of function instead of improvement.

She has few options to control the pain and inflammation of her conditions due to many sensitivities and drug allergies. Her rheumatologist, Dr. (name) prescribed lidocaine patches for her pain but she can only use one per day on one location. This provides little relief for widespread pain. Currently she is on Cymbalta for fibromyalgia. There has been no improvement so far.

Although Ms. \_\_\_\_\_ has been very compliant and pro-active regarding his condition, the synergistic effect of her medical conditions makes it impossible for her to work in any capacity. She cannot use the keyboard and type, or perform any repetitive movements with her hands for more than a few minutes. She has difficulty turning the pages of a book, preparing food, chopping vegetables, lifting pots and pans, lifting and carrying groceries, washing dishes.

She has trouble with personal hygiene...such as washing hair and getting in and out of the tub. She also has trouble grasping things, holding arms overhead, often drops things, is unable to fold laundry and cannot stand for very long. Clothing must be loose and oversized to allow her to dress with her limited range of motion.

Some days she has very poor concentration and problems with short-term memory and issues with word retrieval. I have encouraged her to remain as active as possible as she can when she is able, but the unpredictable nature of her CFS combined with her fibromyalgia and Osteoarthritis

maker her unable to work on any consistent and predictable basis. She requires numerous rest periods between minor daily activities and frequent trips to the bathroom when her bladder inflammation flares.

Two hours of any activity, even sedentary, can cause exacerbation of symptoms, and sometimes appearance of new ones. She can have several days following over-exertion when she can hardly get out of bed. On her most recent visit, she complained of having problems with balance. At this time, there is no known standardized treatment for ME/CFS. It is a challenging condition requiring trial and error treatment per symptom and a restricting of activities. Given the clinical picture so far, it is highly unlikely she will improve in the next 12 months. Her osteoarthritis is chronic and will likely worsen and affect other joints over time. I fear that overuse of her less affected right hand will cause accelerated disease in that hand. It is very unlikely that her fibromyalgia will improve enough to allow her to work, given her current conditions, her limited options for pain relief, and her lack of response so far to Cymbalta. Lyrica is chemically very similar to gabapentin and her rheumatologist is reluctant even to attempt it due to her reaction to gabapentin as adverse reaction can be severe. All appropriate treatments thus far have provided no improvement in her level of function.

Thank-you for allowing me to provide this information on behalf of my patient.  
Please feel free to contact me with any questions.

## Helping Your Doctor Prepare the Medical Report

The applicant, as already discussed, should definitely give his/her doctor(s) a copy of the Guideline “Providing Medical Evidence for Individuals with ME/CFS” – see above for the link. The applicant might want to alert their physician to summary versions of the 1994 CDC definition and the 2003 Canadian definition (see links above) Also the July 2020 U.S. ME/CFS Clinician’s Coalition’s Paper, Diagnosis and Treating ME/CFS is an excellent summary hand-out for physicians.

<https://drive.google.com/file/d/1SG7hlJTCSDrDHqvioPMq-cX-rgRKXjfk/view>

Also, the ME/CFS Physician’s Primer on this website is a great educational tool for physicians.

Also by giving your physician the Bernard Kansky Memo, the Incapacity Checklist, and perhaps Letters # 1, #2, and/or #3 (but only if you explain that each of these letters requires additional information), you will be helping your doctor prepare a strong letter on your behalf. Don’t forget letter # 4 – but you don’t want to overwhelm your doctor. Maybe #4 is enough.

The Mass Disability Law Center in its booklet, *"How to Secure and Protect your Social Security Disability Benefits,"* suggests that patients should, if possible, ask their doctors and other providers to send them (the patients) copies of all the reports and documents to be submitted to

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

Social Security. The patient him/herself could then submit the duplicate documents to Social Security -- after making copies of the documents for his or her own records. By this method the patient would make sure that Social Security would get all the records in a timely manner – just in case there are any delays in the physician’s submission of records.

*There are two advantages to such a procedure:*

1 -The patient will be able to make copies of all records sent to Social Security. Possession of these records can be useful during the various appeal stages.

As suggested above, this procedure also allows the patient to review all records before they are sent to Social Security. If a particular record or letter is incomplete, then the patient can ask his or her provider to include additional information.

2 - A good alternative to the above procedure is simply to ask your doctors to send you copies of all records that they send to Social Security. This way, you will at least know what has been sent and you will have copies for your own records. Often a patient is too sick to send in records themselves.