

**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 II

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

This Appendix includes the following:

1. ***Memo From a disability lawyer.: Recommended Documentation of CFS Disability to be submitted to Social Security and/or for Private or Employer Disability.*** Based on extensive experience adjudicating 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 CFIDS Symptoms Checklist.*** A comprehensive listing of CFIDS 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/CFIDS, 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. Anthony 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.***

Excerpts from “Documentation for the Social Security Administration’s Adjudication of Disability Claims Involving Chronic Fatigue Syndrome (1997)”

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

B. Excerpts from the Social Security Administration Fact Sheet (publication #64-063): "Providing Medical Evidence to the Social Security Administration for Individuals with

Chronic Fatigue Syndrome - A Guide for Professionals" (1996).

Excerpts from this Fact Sheet explain the type of documentation needed to demonstrate the claimant's functional incapacities: his/her inability to engage in work and other activities.

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 C.F.S. 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 A Disability Lawyer's Perspective: Recommended Documentation of CFS Disability Claim to be Submitted to Social Security and/or for Private/Employer Disability

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. CFIDS/ME & FM 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 CFIDS is not a psychological disorder. See section on cognitive dysfunction.) For more information on issues of psychological disorder in a CFIDS disability claim, see Appendix IV 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 CFIDS who is well respected by colleagues and Administrative Law Judges alike This should be a detailed narrative report describing extent by degree, of 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 CFIDS care physician 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 claimant is totally disabled, both Social Security and the Long Term Disability Carrier expect 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.

[The following are observations 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 CFIDS 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 CFIDS, 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 primary care 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. (See Appendix IV and Ruling.)

Checklist of CFIDS 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 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%)
- Postexertional malaise (50-60%) (a feeling of debility, discomfort or lack of health similar to that experienced at the onset of an illness)
- Symptoms worsened by extremes in temperature
- Multiple sensitivities to medicines, foods, and other substances
- Severe nasal and other allergies (40%) (often 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
- Intolerance of alcohol
- Alteration of taste, smell, hearing
- Twitching muscles (*"benign fasciculations"*)

1. 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)
Tachychardia (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.

Some Tests to be Conducted to Help Determine Objectivity of CFS, CFIDS and/or Disabling 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. Rosatia (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.

I. Excerpts from CFS Social Security Documents

These excerpts when not in conflict with the new Social Security 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.

Documentation for the Social Security Administration's Adjudication of Disability Claims Involving Chronic Fatigue Syndrome

Chronic Fatigue Syndrome (CFS) is characterized by prolonged fatigue and multiple nonspecific symptoms which last 6 months or more and significantly limit normal activities of daily living.

According to the Centers for Disease Control and Prevention, a diagnosis of CFS should be reached only after other possible disease entities capable of causing such fatigue and related symptoms have been ruled out (Annals of Internal Medicine, 121:953-9, 1994). Any indication of the presence of a medical, psychiatric, psychological, or neurological disorder should be resolved by appropriate medical, psychiatric, psychological, or neurological evaluation.

How Social Security Determines Whether a Person is Disabled

Under Social Security law, an individual is considered disabled if he or she is:

unable to do any substantial gainful work activity because of a medical condition (or conditions), that has lasted, or can be expected to last, for at least 12 months, or that is expected to result in death; or, in the case of an individual under the age of 18, if he or she suffers from any medically determinable physical or mental impairment that causes marked and severe functional limitations.

The medical condition(s) must be shown to exist by means of medically acceptable clinical and laboratory findings. Under the law, symptoms alone cannot be the basis for a finding of disability, although the effects of the symptoms may be an important factor in our decision regarding whether a person is disabled.

Once a medically determinable impairment has been established, and it is one which could reasonably be expected to cause pain, fatigue, or other symptoms, then the symptoms must be considered both in evaluating the severity of the impairment and in assessing the individual's functional capabilities in the subsequent steps of the disability evaluation process.

SSA uses a five-step sequential evaluation process to determine disability. Step one is simply whether or not the individual is working at a substantial level. Step two determines whether the individual's impairment is severe or not severe. Step three moves to the medical evaluation criteria known as the Listing of Impairments which describes impairments for each of the body systems that are presumed severe enough to be disabling, in the absence of work activity. If an individual's clinical signs, symptoms, and laboratory findings are the same as or equivalent in severity to those specified in a given listing, the individual is found disabled on medical grounds alone at step three.

If the individual has a severe impairment but it does not meet or equal the severity of a listed impairment, further evaluation specifically addressing the individual's functional capabilities must be done. This is known as the residual functional capacity (RFC) assessment. It determines what the person can still do despite the functional limitations imposed by his or her impairment, including symptoms, and is used to decide if the individual could be expected to return to past work.

If past work is precluded based upon the RFC, a determination is made regarding the individual's ability to perform other work within his or her functional capacity, given the additional factors of age, education, and past work experience. If other work is also precluded under this determination, then disability is established.

For a child under age 18, the evaluation process stops at the third step and assesses whether a child's impairment(s) causes marked and severe functional limitations.

In order to perform the complete evaluation process, SSA must have detailed medical and non-medical information which presents a comprehensive picture of a person's medical condition and functional limitations, both physical and mental, over a period of time sufficient to determine disability under the law.

Medical Evidence

Longitudinal medical records (i.e., records describing the illness over time) are very important for disability claims evaluation under Social Security and are especially significant

in assessing the presence and severity of CFS. Every effort should be made to provide as much detailed longitudinal information as possible, either with photocopies of examination and treatment records or in a narrative report (or both).

Ideally, a medical report should include the following elements:

- Medical history;
- Clinical findings (such as the results of physical and/or mental examinations);
- Laboratory findings (such as the results of blood tests or psychometric testing);
- Diagnosis;
- Treatment prescribed with reports of response and prognosis; and
- A statement by the treatment source detailing what the patient can still do despite the effects of the impairment.

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
- A detailed description of how the impairment(s) limits the patient's ability to function in the activities of daily living.

Signs and symptoms of CFS which should be addressed may include:

- sore throat,
- tender cervical or axillary lymph nodes,
- muscle pain,
- multi-joint pain without swelling or inflammation,
- generalized headaches of new origin,

- unrefreshing sleep,
- post-exertional malaise,
- impaired memory or concentration,
- chronic intermittent fever,
- muscle wasting,
- neurological deficits,
- difficulties with vision, and
- other mental abnormalities.

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.

Laboratory Findings:

There are no specific laboratory findings that document CFS, but longitudinal studies in the record may include the following tests:

- complete blood count with leukocyte differential;
- erythrocyte sedimentation rate;
- thyroid-stimulating hormone;
- urinalysis;
- serum levels of:
 - alanine aminotransferase
 - total protein
 - albumin
 - globulin
 - alkaline phosphatase
 - calcium
 - phosphorus
 - glucose
 - blood urea nitrogen

- electrolytes
- creatinine

Additional tests to exclude other diagnoses may also be in the record.

The results of tilt-table testing to evaluate neurally-mediated hypotension may also be included; these results may be abnormal in persons with CFS.

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.

II. Excerpt from Social Security Fact Sheet, Publication #064-063: Providing Medical Evidence to the Social Security Administration for Individuals with Chronic Fatigue Syndrome

A Guide for Health Professionals

...If the medical evidence alone shows that a person is clearly disabled or not disabled, we decide the case on that information. Otherwise, we go on to consider other factors, such as functional capacity in light of the person's impairment(s), age, education, and work background. For a child under age 18, we generally consider the child's ability to function independently, appropriately, and effectively in an age-appropriate manner...

...You should also include a statement of your opinion about what work-related activities the person can still do despite his/her impairment. Tell us your opinions about both physical and mental functions and, to the extent possible, the reasons for your opinions, such as the clinical findings and/or your observations of the person. These opinions should reflect the person's abilities to perform work-related activities on a sustained basis, i.e., 8 hours/day and 5 days/week. Your descriptions of any functional limitations you noted throughout the time you treated the patient are very important. Examples of work-related functions include:

--Physical work-related functions: walking, standing, sitting, lifting, pushing, pulling, reaching, carrying, and handling.

--Mental work-related functions: The ability to understand, remember, and carry out simple instructions, the ability to use appropriate judgment, and the ability to respond appropriately to supervision, co-workers, and usual work situations, including changes in a routine work setting...

...Although you may reach a diagnosis of CFS on the basis of your patient's symptomatology (after ruling out other factors), the Social Security law requires that a disabling impairment be documented by medically-acceptable clinical and laboratory findings. Statements merely recounting the symptoms of the applicant or providing only a diagnosis will not establish a medical impairment for the purposes of Social Security benefits. We must have reports documenting your objective clinical and laboratory findings. Thus, it is essential that you submit all objective findings available concerning your patient's condition, even if they relate to another disorder or establish that the person has a different condition.

SSA Pub. 64-063

ICN 953800

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' CFS disability claims. These letters 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.

Note: These sample letters should only be used as a supplement to the other instructive material in this booklet. The memo in this Appendix is the best guide for doctors in preparing the medical letter.

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 CFS rather than the *cause* of the 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 chronic fatigue syndrome. 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 overhead 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.

Helping Your Doctor Prepare the Medical Report

By giving your doctor the latest Social Security Memos in this Appendix, the 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.

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 Social Security. The patient him/herself would then submit the documents to Social Security -- after making copies of the documents for his or her own records. The patient, in this procedure, takes the responsibility for collecting and submitting some records to Social Security.

There are two advantages to such a procedure:

I. By acting as *collector* you make sure that as complete a record as possible gets submitted to Social Security in the shortest possible time period. You can keep track of the records you are receiving, and you can make follow-up requests to your provider(s) if a record or letter is incomplete, or if there is too long a delay. Sometimes Social Security does not pay close enough attention to obtaining complete

records or making follow-up requests if a record is not sent. Often an applicant will be denied because Social Security did not receive a complete record.

2. 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.

The big drawback to the above procedure is that often the CFS patient is too sick and exhausted to do the work of collecting and submitting documents to Social Security. The patient should not try to act as collector unless s/he can really do it properly; unless you can do the job right you should let your doctor and Social Security handle it directly. It's a big job to collect medical records, keep track of them, copy them, and then make sure they all get mailed. Perhaps a healthy family member would take this on; but again, the family member should understand what is involved, and should be willing and able to do the job right.

Note: 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.