HOW TO APPLY FOR SOCIAL SECURITY DISABILITYBENEFITS 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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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 many 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

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

How To Apply For Social Security Benefits If You Have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME-CFS)

I. *The Application Process*

People with ME-CFS who are applying for Social Security benefits should know that the application process can be sometimes be difficult and frustrating. However, despite the difficulties of applying, if you are willing to take a "stick-to-it" attitude and not give up, *chances are quite good that you will be awarded benefits.*

If you are prepared for some difficulties and frustrations at the beginning, it will be easier for you to cope; setbacks can be recognized as temporary and can act as an incentive to do what's necessary at the next stage. You should keep in mind that these setbacks do not at all prevent a favorable, final outcome.

At the outset, you need both to be psychologically prepared for difficulties and to have hope.

If you have a reasonably serious case of ME/CFS and are unable to do even light, sedentary work on any scheduled, ongoing basis, and this situation is expected to be continuous for at least a year, then chances can be quite good that you will ultimately win benefits.

You must stick with the process and provide Social Security with all necessary information, including seeing Social Security's physicians or specialists (unless you can persuade Social Security that such appointments are unnecessary or a hardship - but if Social Security insists, such appointments should be kept).

It is also crucial to file the necessary appeals within the required time limits.

Very Important

Very often people are rejected at both the initial application stage and at the reconsideration stage without a complete and fair review of their cases. Such rejections at the first two stages are common and to be fully expected - so the applicant should not be devastated or give up if s/he receives such a rejection.

The fact is that applicants may receive a fair evaluation of their case only during the third stage - at the hearing before the administrative law judge. Most often, it is only at this hearing stage that ME/CFS applicants are finally awarded benefits. So an applicant must continue with the process until s/he reaches the third stage - this is when the person's chances are best.

However, the applicant must not think s/he doesn't have to make *a full effort to provide Social*

Security with all necessary information at the first and second stages. It is absolutely necessary to make an all-out effort to comprehensively document your illness at the first two stages.

The applicant should also realize that although s/he may have to wait many months for a favorable decision by the administrative law judge, the wait is not in vain since a favorable decision means that benefits will be awarded retroactively.

II. *When to Obtain a Lawyer*

During the initial application process, if you have questions or concerns about either how to apply or how to fill out the application, you should obtain the advice of an advocate (not necessarily a lawyer) familiar with the disability process. You can contact the Mass ME/CFS Disability Committee through our website (www.massmecfs.org). During the application stage, you do not necessarily need legal representation; however, getting sound advice early on may help you avoid mistakes that could later be detrimental to your claim.

If you are rejected at the first two stages, you must obtain a lawyer or legal representative to present your case before the administrative law judge. The lawyer should be a specialist in, and have had experience with representing Social Security disability cases – and also be reasonably knowledgeable about your actual illness: ME/CFS, fibromyalgia, or other illness.

If you are of low income you can obtain a lawyer through the local legal assistance office. Otherwise, the lawyer can be hired on a contingency basis, which means the lawyer only receives compensation (a percentage of the retroactive disability benefit) if you win your case. If you are not of low income, the Mass. ME-CFS Disability Committee can refer you to a lawyer who will handle your case on a contingency basis. The contingency fee is limited to a maximum of 25% of the retroactive award, but cannot exceed $6,000. The final attorney's fee is determined by Social Security. You should always obtain a *written* fee agreement if you have a private attorney. An attorney may also charge for various expenses, like copying documents, etc.

If you are already receiving benefits from an employer-related disability policy, the insurance company may be willing to pay the cost of an attorney. But you should definitely choose your own attorney rather than accepting an attorney chosen by the insurance company. The Mass. ME/CFS&FM Association keeps a list of lawyers who have successfully represented applicants for Social Security disability and employer-related disability policies. Get in touch with the Association at https://www.massmecfs.org/ through the Contact Us portal. Also, if you hire an attorney for long-term disability, make sure that the lawyer takes only a reasonable percentage of your disability benefits. Find out the normal fee percentage of your benefits. Also, do not accept a fee that you to pay the lawyer a percentage of your lifetime benefits. For more on these fee agreements go to https://www.massmecfs.org/disability-links/72-attorney-fee-agreements-for-disability-claims-what-is-a-fair-and-legal-agreement.

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III. ***When to Apply for Disability***

To be eligible for Disability (SSDI or SSI), a person with ME/CFS must no longer be able to do even light, sedentary, part-time work, on any predictable basis, and his/her inability to work must be expected to last (or has lasted) for at least one year.

This means, first (with rare exceptions), that a person should not be working, even part-time, when s/he applies.

Second, you should apply as soon as possible after you become disabled and unable to work. To be found eligible, however, Social Security must determine that your inability to work is expected to last for at least a year. If you apply within a short time after leaving work, ask your doctor to include in his/her letter to Social Security that you will not be able to return to work for at least a year. Or state that your ability to return to work is not expected to change (or will be unpredictable) for at least a year.

Of course people with ME/CFS have often been out of work many months before they apply for disability. If you already have been out of work at the time you apply, your period of unemployment should count toward filling the one-year stipulation.

To properly pursue your application, you and your doctors must document as fully as possible your diagnosis of ME/CFS and/or FM. Proper diagnosis of ME/CFS according to established medical guidelines require that the symptom complex must have lasted for at least six months. Therefore, until you have been sick for close to six months, it may be difficult for your doctor to confirm a ME/CFS diagnosis. However, this six-month diagnostic period is usually not a problem in applying for disability, since many patients have been sick for at least six months before they apply for disability. However, your doctor may determine that your illness is sufficiently certain that s/he can make the diagnosis in less than six months.

The basic rule is that you should apply as soon as you are no longer able to work, regardless of certainty of diagnosis.

If you are no longer able to work, Social Security must accept your application. There are times when someone at Social Security may be unfamiliar with ME/CFS (even in 2020!), or for some other reason try to discourage you from applying. If this happens, you should insist on your right to file an application. If Social Security does not let you file, you should immediately contact the Mass. ME/CFS Disability Committee through our contact us function – or the Disability Law Center in Boston referenced above (617-723-8455).

IV. ***Your Doctors' Letters to Social Security***

In order to, successfully medically document your disability to Social Security through the various stages of the application and appeals process, *it is necessary to develop and maintain a constructive and ongoing relationship with a physician who can medically verify your disability.*

After you have been approved for disability, you should continue to maintain an ongoing physician relationship since Social Security will require you to medically document your disability during periodic Reviews, which occur at various intervals**.** Maintaining an ongoing physician relationship is very important in obtaining and maintaining your Social Security Disability. This is even more important if you are receiving long-term disability through an insurance company, since they may want updates every 3-6 months.

Normally, in the application, Social Security will ask you to list all the doctors who have treated you for your disabling illness(es). Social Security should send the paperwork to your doctors to enable them to document your disability.

Very important: In addition to these submissions, you should ask at least one of your doctors to write a comprehensive Disability Medical Report (a one to two page letter) documenting, in detail, how your diagnosis was made: all your medical signs, symptoms, and lab tests should be detailed. In addition, your doctor should document the physical and cognitive limitations that prevent you from working. The Report should also give some specific detail in your inability to perform work tasks and activities of daily living. (See Appendix IV for model Disability Reports/letters.)

The Necessity of Obtaining and Documenting a Definitive Diagnosis of ME-CFS or Fibromyalgia from a Qualified Physician

In order to qualify for Social Security Disability programs a person must have a *“medically-determinable impairment”* which must be diagnosed and documented to Social Security by an MD physician. Also, the severity of the person’s functional limitations must be documented, that is, the inability to perform work tasks and activities of daily living.

The Social Security Administration has issued two Rulings that provide the standards for the proper evaluation of ME/CFS and Fibromyalgia disability claims:

SSR-14-1p Titles II and XVI:” Evaluating Claims Involving Chronic Fatigue Syndrome”;

2012 Social Security Administration Policy Interpretation Ruling SSR 12-2p: Titles II and XVI: “Evaluation of Fibromyalgia”

The Social Security Ruling on Evaluating CFS Disability Claims:

In 2014 the Social Security Administration issued a critical new Ruling: *SSR-14-1p Titles II and XVI: Evaluating Claims Involving Chronic Fatigue Syndrome”.* The Ruling establishes the guidance by which Social Security evaluates CFS disability claims and reviews for both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). You can obtain a copy of the Ruling at: https://www.ssa.gov/OP_Home/rulings/di/01/SSR2014-01-di-01.html. If you give a copy of the Ruling to your doctor it may assist him or her in documenting your illness and disability.

A full evaluation of the Ruling is included in Appendix I – please familiarize yourself with it as the Ruling is the guide on how your claim should be documented.

Note: The Ruling only uses the term "CFS" in its title, but also notes that some medical experts consider ME to be a subtype of CFS. Hence, when referring directly to the Ruling, the term "CFS" will be used. However, the Guidance for doctors, see below, uses the term ME/CFS.

Just as important is the more recent SSA document: *"Providing Medical Evidence for Individuals with Myalgic Encephalomyelitis Chronic Fatigue Syndrome (ME/CFS)"* https://www.ssa.gov/disability/professionals/documents/64-063.pdf This document provides an important Guide specifically to doctors for documenting your illness. Your doctor should submit a completed copy to Social Security. Take a copy of this form to your doctor. The form will also assist your doctor(s) in writing the Disability Medical Report. If the doctor has time s/he could scan through the Ruling itself for more guidance,

The Ruling provides a comprehensive explanation of the medical signs, symptoms and lab and other tests that document the ME/CFS diagnosis. The doctor should also provide evidence that other diagnoses and conditions have been ruled out.

The Ruling also provides that medical evidence consistent with a CFS diagnosis that is not listed in the Ruling can also be used to help establish a diagnosis.

The Ruling requires doctors to back-up their documentation of medical signs/lab tests and functional limitations from a longitudinal clinical record covering the past 12 months. To do this the physician can append to the medical report copies of his notes from each office visit as well as lab test reports. It is important for your doctors to keep non-abbreviated office notes that document your objective signs and symptoms, and their severity, at each visit so that Social Security can verify your diagnosis.

Diagnostic Criteria cited in the Ruling for the determination of CFS as a "medically-determinable impairment:

For CFS, the 2014 Ruling primarily relies on the 1994 Centers for Disease Control CFS diagnostic criteria for making and documenting the diagnosis. However, the Ruling also *"to some extent"* accepts the 2003 Canadian ME/CFS Criteria as well as the 2011 ME International Consensus Criteria (Adult and Pediatric) as further diagnostic confirmation.

As a result of recognizing the two more recent Diagnostic Criteria, the 2014 CFS Ruling includes a broader and more detailed listing of signs, symptoms and laboratory tests for the illness – thereby allowing claimants and physicians to better document and validate the illness. The best approach is to first diagnose using the 1994 CDC Criteria, and then to use the two newer Criteria to further document the diagnosis. See Appendix II for a summary of the 1994 CDC Criteria.

In 2020, the U.S. Centers for Disease Control and Prevention (CDC) has adopted a new Diagnostic Criteria: *the 2015 Institute of Medicine ME/CFS Diagnostic Criteria*. This Criteria has fewer diagnostic requirements than all of the previous criteria. However, the current Social Security

Ruling does not yet recognize the 2015 Criteria, so we advise that physicians use the older 1994 Criteria, and additionally the 2003 or the 2011 Criteria already explained. However, if the patient meets only the current IOM/CDC criteria, then the physician should diagnose by the new CDC criteria.

Our Association website in its section on Diagnosis provides, in summary form, the 2003 ME/CFS Canadian Diagnostic Criteria, the International Consensus Criteria, and the 1994 Centers for Disease Control CFS diagnostic Criteria. Applicants should use these links to familiarize themselves with how ME/CFS is diagnosed. The Criteria can also be printed out and given to the patient's physicians.

The link for the 2003 Definition is: https://www.massmecfs.org/diagnosis?start=1

The link for the 2011 International Criteria is: https://dxrevisionwatch.files.wordpress.com/2011/10/international-me-consensus-criteria.pdf

The link for the 1994 CDC Criteria (which still is the preferred Criteria for Social Security) is: https://www.massmecfs.org/more-resources-for-me-cfs/134-1994-cdc-definition?start=2

The reader should familiarize themselves with the various issues in diagnosing the illness at: https://www.massmecfs.org/diagnosis

The new CDC-IOM Diagnostic Criteria can be found at https://www.cdc.gov/me-cfs/healthcare-providers/diagnosis/iom-2015-diagnostic-criteria.html

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The Fibromyalgia Ruling, currently operable in 2020, establishes criteria for how Social Security Disability claims examiners and administrative law judges are to evaluate fibromyalgia disability claims – and the standards that must be met for the approval of these claims. This Ruling covers both FM SSDI and SSI disability claims. See Appendix III for our explanation and evaluation of this Ruling and a link to the Ruling itself.

The 2012 Social Security Fibromyalgia Ruling designates the Criteria to be used in diagnosing FM: the "1990 ACR Criteria for the Classification of Fibromyalgia", and the "2010 ACR Preliminary Diagnostic Criteria".

More on Your Doctors' and Your Providers' Letters

Your doctors' letters to Social Security, along with other medical documentation, are important in obtaining a favorable decision.

Letters from your doctors should seek to accomplish the following two objectives:

1) The letters should fully establish and document your ME/CFS diagnosis.

2) These letters should establish that, as a result of your illness, you can no longer do any work, even light, sedentary, part-time work on any continuing, scheduled basis. Your doctor should state that this inability to work is expected to last at least 12 months.

Generally, 2 types of doctor's letters are submitted:

1) The "Disability Medical Report" or letters which fully establish and document both the ME/CFS diagnosis and the patient's inability to do any scheduled work. This type of letter, usually one to two pages, should fully establish and document your ME/CFS diagnosis and your inability to do any scheduled work ("residual functional capacity"). You should obtain this type of letter from at least one physician *who recognizes and understands ME/CFS* and who is willing to write such a comprehensive letter. If you can obtain this type of comprehensive letter from more than one doctor, you should definitely do so.

Often your primary care doctor, who may not be experienced with ME/CFS, can write a very useful letter explaining the severity and chronic nature of your symptoms and illness as well as how disabled you are from working and daily activity. He or she may not be well-versed in making an ME/CFS diagnosis. In this case you will need to see a specialist in the illness. Do take printed information to your doctors about the illness. The U.S. ME/CFS Clinical Coalition provides an informational hand-out to doctors on the illness https://drive.google.com/file/d/1SG7hlJTCSDrDHqvioPMq-cX-rgRKXjfk/view

2) The second type of letter, which acts to supplement the comprehensive letter just described documents a particular element or aspect of the illness. This type of submission would include the results and evaluation of neuropsychological testing or the results (including lab tests) of neurological, hematological, immunological, or psychiatric examinations which support your ME/CFS diagnosis. Naturally, a specialist would write this type of letter. Where possible, the provider should explain how the findings would prevent you from working.

This category of supplementary letter could also include letters documenting your inability to work (or more technically, your "residual functional capacity"). Such letters might be written by a rehabilitation specialist, an occupational therapist, physical therapist, etc. Letters documenting your physical incapacity to work can also be submitted by people who are in a good position to observe your limitations and difficulties in daily life, including family, friends, former employer, clergyman, etc.

People writing these letters should give specific examples (from their actual observations) of your difficulties in performing various household tasks, in meeting your own personal care needs, or in performing your other family responsibilities. Friends might write of their observations of the decline of your health, your having to leave your job, or your having to give up your social life or community work. Finally, letters from people with whom you have a more professional relationship, such as teachers, clergy, former employers, etc. can be very helpful. Again, these letters should attest to the disabling changes and limitations caused by your illness.

You should ask your doctor(s) and anyone else sending letters or medical records to Social

Security on your behalf to also send you a copy of what they have been submitted. By doing so, you will know exactly what documents have been sent and when; you will also know what information has been included in the documents (in case you need to ask your provider to send Social Security additional information). Finally, having copies of the documents will be very helpful if you need to appeal.

Also, if you know that your physician's office is slow in making submissions, you can send the documents yourself as well – there is not a problem with duplication and timeliness is important.

For more information and suggestions on how to work with your doctor(s) in preparing and submitting reports to Social Security, see the Appendix IV.

Important information for individuals with fibromyalgia applying for Social Security benefits:

Individuals with a diagnosis of fibromyalgia may have greater difficulty than those with ME/CFS in obtaining approval of their claim for social security benefits. Many medical authorities are of the opinion that ME/CFS and fibromyalgia are either the same illness or are very closely related illnesses. Therefore, when applying for disability benefits, a person with a diagnosis of fibromyalgia would be advised to determine whether or not s/he might also obtain a diagnosis of ME/CFS - although most people with FM do not also have ME/CFS. However, about 80% of ME/CFS patients also have fibromyalgia. Very often a diagnosis of fibromyalgia is obtained after consulting with a rheumatologist. Following such a diagnosis, many individuals have found that they can also obtain a ME/CFS diagnosis by consulting a doctor familiar with ME/CFS such as an Infectious Disease Specialist. Some patients do have both illnesses.

Your Doctors' letters continued:

It is not enough for your doctor in his/her letter simply to state that you have ME/CFS and leave it at that. First, your doctor should document the relevant findings produced by the history, physical, and other examinations and the laboratory testing. In general, any lab tests which are indicative of infection, immunological or other neurological abnormalities should be submitted.

(Please again see the Social Security document "Providing Medical Evidence for Individuals with ME/CFS – A Guide for Health Professionals" as to how your physician(s) should document signs, symptoms, and laboratory tests. Also, see the 2014 Soc. Sec. Ruling Appendix I for more detailed information on the type of medical and functional limitation documentation needed.)

Also see Appendix IV for a further list of diagnostic tests compiled by Dr. Charles Lapp.

In most cases the physician would then document that the evaluation had found no illness or condition that would exclude a diagnosis of ME/CFS, and would therefore indicate an alternative diagnosis. If the individual clearly has ME/CFS, and there is the presence of an exclusionary condition, the doctor can still provide a ME/CFS diagnosis. Your doctor should list each and every one of your symptoms, past or present (with this illness, symptoms can vary over time).

The doctor should then describe the character and date of ME/CFS onset, the progression of your illness since onset, including changes in and intensification of the illness and symptoms over time. Special attention should be given to describing the severity, frequency, duration, and the recurrence of the major symptoms.

In addition to your doctors' letters documenting your symptoms, you may as part of your application complete and submit the ME/CFS symptom checklist (see Appendix IV.) You and your doctor may also wish to use the list as an aid in compiling and documenting your symptoms for his or her letters and reports.

Also within his or her letter, the doctor may wish to include any other diagnoses found during the medical evaluation, including those illnesses or conditions that do not themselves explain the ME/CFS illness complex of medical signs, symptoms and lab results. These are the so-called *co-occurring conditions* whose presence do not rule out a diagnosis of ME/CFS - see Appendix II.) Such conditions may include Fibromyalgia, chemical sensitivity disorder, and other illnesses.

There are also medical conditions whose presence *may* exclud*e* and ME/CFS diagnosis. The 1994 CDC definition – Appendix II – lists some of these conditions. One can have some exclusionary conditions and also have ME/CFS as long as both conditions are carefully documented as separate illnesses. For instance bi-polar illness is an exclusionary condition as suggested by the 1994 CDC criteria – but a person with bi-polar clearly can have ME/CFS at the same time. (A person with bi-polar can also have one of a number of physical illnesses as well.) Major depression might be an exclusionary illness if it preceded ME/CFS – however, a person could have both illnesses as well. A physician must be found who is able to provide very credible evidence that a listed exclusionary illness exists alongside a valid ME/CFS diagnosis.

Your doctor should specifically describe all treatments, including medications which have been prescribed either currently or in the past. The results of each treatment should be reviewed. Medication for dealing with the secondary depression (depression caused by the illness) often does not help any of the other ME/CFS symptoms - this should be noted if it is in fact the case.

The preceding discussion has focused on your physician's letters. A number of attorneys with wide experience in representing Social Security Disability cases stress the increasing importance placed by Social Security on <u>your doctor's treatment notes</u> as a means of verifying your disability.

Attorney Fay E. Fishman is a Civil Practice attorney, with an emphasis on Social Security, from Minneapolis, Minnesota. She has handled many successful appeals for persons with ME-CFS. She stresses that the doctor's regular treatment notes can be a critical element in either helping or hurting the patient's disability claim. The patient should suggest to the doctor that during the course of treatment the doctor should provide in his or her treatment notes the following information as necessary documentation in the event of a future disability claim.

Attorney Fishman writes:

> First, on each visit, examinations which document the fatigue and symptoms of ME/CFS must be performed. Temperatures should be taken and noted, throats must be examined, and nodes must be palpated.
>
> Second, the symptoms complained of by the patient must be noted (including night sweats, sleep disturbances, body aches, extreme fatigue, nausea and cognitive dysfunction, etc.) at each examination. The comment that, "The patient remains unchanged," does not help a claim. Further comments such as, "the patient is somewhat improved," or "patient's energy level has increased" without further explanation can hurt a claim.
>
> Again, medical records in the legal system are primary evidence, which determine whether a patient can collect disability benefits.

In an article entitled, "Helping Fibromyalgia Patients Obtain Social Security Benefits" by Attorney Joshua W. Potter, published in the *U.S.A. Fibrositis Association Newsletter;* Attorney Potter writes the following:

> When a physician recognizes that a patient may become a candidate for Social Security Disability payments, chart entry should be made in detail... Every patient visit should result in entries concerning physical capacities for lifting, bending and carrying (verified with measured weight); time durations for sitting, standing and walking (by history); the nature, location and intensity of pain (by history); psychosocial and adaptive behavior, including the ability to interact appropriately with others, follow instructions, and adhere to a regular work schedule; and the complex of expressive symptoms.

Important: At the end of this booklet you will find Appendix IV entitled, "Helping Your Doctor Prepare Your Medical Report." In this Appendix is *a memo From Bernard A. Kansky, Esq.: Recommended Documentation of ME/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.

Also included in the Appendix IV are several sample doctors' letters which help demonstrate how a strong and effective letter can be written. However, please read the instructions concerning these letters carefully before showing the letters to your doctor, since each letter lacks certain necessary information - only by looking at the combination of the letters is it possible to obtain a picture of what a model letter should look like.

Finally, another section of Appendix IV explains how you can take some initiative (depending on how sick you are) in helping your doctor prepare the strongest and most effective report possible.

One suggestion is to ask your doctor(s) to let you see his/her letter (and the Social Security questionnaire) before s/he mails them 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. In any case, you should be sure to ask your provider to send you copies of all letters and records submitted to Social Security. It is important for you to have copies for your records. Of course, some physicians may be hesitant to provide these letters and records, so just do what you can; but emphasize that the documentation should be sent to Social Security as soon as possible.

Supplementary Diagnostic Materials

Letters by specialists supporting your diagnosis, including the results of specialized neurological, hematological, immunological, or neuropsychological testing should be submitted.

Neuropsychological testing is achieving importance as a ME/CFS diagnostic tool and is recognized as such by Social Security. This type of test, when administered and interpreted by a skilled specialist, can distinguish between symptoms caused by psychological disorders and symptoms caused by more organically-based illnesses such as ME/CFS. *See the appendix VI on neuropsychological testing and depression.*

Very Important: Interpretation of these tests must be done by a specialist experienced in analyzing the tests in relation to ME/CFS - otherwise the tests could be interpreted incorrectly with potentially negative effects on the disability application.

The CDC diagnostic criteria require that a CFS diagnosis rule out primary depression as an alternative diagnosis. If necessary, your doctor, in his letter, may state that *your illness and symptoms are caused by ME/CFS and that your symptoms cannot be accounted for by an alternative diagnosis of primary depression.* (Neuropsychological testing can help differentiate ME/CFS from a diagnosis of primary depression, as long as the tester knows how to distinguish the illness from depression.)

Once a firm diagnosis of ME/CFS is established, the doctor may document any diagnosis of *secondary* depression caused by the patient's struggle with the effects of ME/CFS. It is very important that the doctor, when discussing depression, distinguish between primary depression (which could cause at least some of your symptoms) and secondary depression (which would be a result of your symptoms). *See Appendix VI on depression for the advisability of including a diagnosis of secondary depression in your medical report.*

If you are applying for private disability, you must read item 6 on page 98 of Appendix VI, as well as appendix IX on Private Disability.

Finally, when you apply for reconsideration or for an appeal hearing, you should ask your doctor for follow-up letters to supplement his original evaluation - these letters would review your current status, state any new diagnostic findings and would describe changes in the illness and symptoms since the last letter.

Very Important Note on Multiple diagnoses: Your doctors' letters should also fully document all other medical conditions which, in addition to CFS, contribute to your disability. Often your case will be stronger if there are additional diagnoses which are not at variance with the ME/CFS diagnosis and which increase your overall level of disability.

Documenting Your Inability to Perform Tasks ("Residual Functional Capacity")

As part of your Disability Medical Report, or the letters of other providers, the provider must document in some detail how your illness prevents you from performing even light, sedentary, part-time work on any continuing basis.

The doctor or provider should describe how and to what extent your illness and symptoms limit your ability to carry out necessary activities and tasks, including household and personal care activities, occupational tasks, and social activities.

Important: Please refer first to the new Rulings for guidelines on how you and your doctor(s) should document your inability to work and perform daily tasks. Please see the section "Documenting the PWC's inability to Work" in the summary of the Ruling in Appendix I, as well as the "Guidance for Physicians". Use the rest of the information in this section, just below, (and also in Appendix IV) as a supplement, when applicable, to the guidelines set forth in the Ruling. These guidelines will directly assist your doctor(s) in documenting (in his/her medical reports) your inability to work. The guidelines specify the types of limitations and incapacities which your doctor(s) should document in the report.

The doctor should assess your inability to perform these activities and tasks according to both the intensity and duration of the task. S/he should note how the intensity and duration of various tasks cause your symptoms to become worse. Special emphasis should be given to describing the intensity and type of *the pain, fatigue,* and *disorientation* caused by your efforts to carry out various activities.

The doctor should document the chronicity of these various limitations - how long these limitations have lasted - and summarize how your capabilities have changed or become more and more limited as your illness has progressed.

Your doctor should give several specific examples of the limitations in your daily household activity, personal care, and social activities caused by the illness - as well as a description of the detrimental effects (including pain, fatigue, disorientation, and needed recovery times) resulting from such efforts. Such examples might include your difficulty performing basic household tasks such as washing dishes, walking to the store, cleaning the house, etc. If you are forced to wake up late or to lie down or nap at intervals during the day, this should be noted. If ongoing activities beyond a couple of hours cause your symptoms to worsen, specific examples should be given. If your social activities have been severely curtailed by the illness, examples should again be given.

The doctor should also summarize your limitations regarding your present capacity to perform occupational tasks, related both to your former employment and your ability to perform light, sedentary work, part-time on an ongoing basis. If you have neurological impairments the doctor should assess limitations in concentration and short-term memory. The doctor should assess the effects of pain and fatigue resulting from various activities, including intermittent or prolonged sitting, lifting, walking, etc.

It would be helpful if the letter describes how your ability to perform at your job became more and more difficult as your illness developed.

Assuming your limitations are severe and chronic, your doctor should state that you are disabled and completely unable to work, and that this situation is not expected to change for at least a year or longer.

In most cases, doctors will not describe most of your functional limitations in great detail but do ask him/her to summarize your limitations - especially with regard to chronicity and pain - according to the instructions above, and to give several examples

The Mass. Disability Law Center, in its booklet, "How to Secure and Protect your Social Security Benefits," provides the following short checklist to help in evaluating your inability to work:

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

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

You may want to give a copy of this checklist to your doctor. (See also a copy in Appendix IV.)

Cognitive Dysfunction: Its Limiting Effects on the Ability to Work

Neurological impairments and cognitive dysfunction impairments of thinking, memory, concentration, etc., seriously affect many ME/CFS patients. These impairments can profoundly limit an individual's ability to work.

Factors such as paying attention and concentrating on the job task, performing job activities within a schedule and at a consistent pace, maintaining regular attendance and being punctual, remembering locations and work-like procedures can be severely impacted by cognitive dysfunction.

Adequately documenting these "non-exertional factors" may be crucial to winning a ME/CFS case.

Social Security evaluates disability claims through a chart (GRIDS system) which enumerates major functional and vocational patterns and into which a claimant's residual functional capacity and vocational patterns are inserted. Ordinarily, under this system, anyone found capable of light work is not found disabled.

However, when there are "non-exertional factors," the GRIDS system cannot be rigidly applied. Non-exertional factors, if properly applied, can take the application off the GRID -- thereby relaxing the criteria for claim approval.

Therefore, it is very important for providers to document neurological impairments and cognitive dysfunction in detail. Special attention should be given to showing how these impairments contribute to the person's inability to work (non-exertional factors.)

Note: There is a complicated and substantial problem involved concerning the issue of using psychological factors to take a ME/CFS patient off the GRID. This problem is discussed at length in Appendix VI. If a person is applying for both long-term disability insurance through an employer, as well as SSDI or SSI, then the issue becomes especially serious.

Any supplementary letters describing your occupational and other functional limitations would be helpful if obtained from former employers, rehabilitation or occupational specialists, or any other person (including family and friends) in a position to creditably make such observations.

V. Your Own Description of the Disabling Effects of Your Illness

As part of the application process (and also as part of the various appeal stages), the applicant must give a full description of the disabling effects of the illness and its symptoms on the different areas of his/her daily life, including personal care, household and social activities. This description should be given in detail: one approach is to list each and every symptom and to describe how each symptom limits each of the tasks you perform each day. You may find the ME/CFS symptom checklist (see Appendix IV) helpful in the process of compiling your symptoms and their effects. It is also advised that you take a fairly bad day and go from hour to hour documenting how each symptom impairs your living. You may wish to keep a diary of your illness to facilitate your documentation of impairment. These records may be submitted directly to Social Security.

Note: In answering questions on the Social Security application, it is recommended that while applicants should fully document their illness and disability, they should do so only in the length of words required to provide the necessary and essential information and detail. *Thesis-like answers amounting to many pages in response to each question will only cause Social Security to question whether the applicant might be able to work as a writer, i.e., that the applicant is not disabled.*

If you completed the application entirely by yourself, it is helpful to note how many sessions, of what length, over how many days, were required for completion - and why - due to fatigue, symptoms, cognitive dysfunction, etc. Several sentences should suffice.

Also if you were too sick to complete the application by yourself, and needed help in preparing or transcribing your answers, you should explain this to Social Security. By doing so, you will make Social Security aware that you are disabled to the point you are unable to do this amount of work yourself. Still, even with the help of another, do not send Social Security a lengthy number of pages.

Naturally, if you send a diary, you will probably send more pages, but note that the diary was compiled over a number of months. You should also highlight the essential material in the diary as no Social Security examiner has the time to read a mountain of detail.

Also, on the above issues, see item 11 in Attorney Kansky's third memo in Appendix V.

VI. Contacting Your Congressperson about your Social Security Application

You may wish to inform your congressperson that you are applying for Social Security Disability either at the time you apply or at any time during the application process (including during any of the appeal stages.) Your congressperson is a member of the U. S. House of Representatives in Washington, D.C. After you call your Representative, he or she will contact the Social Security Administration to ask that your case be handled in a fair and timely manner. You can also contact your U.S. Senator for the same assistance. The decision on your case will not be influenced in any way by the fact that you contacted your congressperson; however, there may be fewer delays in your obtaining a decision since Social Security will be aware of your Congressperson's and/or Senator’s interest. It is not at all necessary for you to contact your congress people in order to obtain disability benefits, but doing so may provide some advantage in obtaining a more timely decision, especially if you are encountering an unreasonable delay.