

**HOW TO APPLY FOR
SOCIAL SECURITY DISABILITY BENEFITS
IF YOU HAVE
MYALGIC ENCEPHALOMYELITIS/
CHRONIC FATIGUE SYNDROME
(ME/CFS)**

With Additional Information on Applying for Benefits
If You Have Fibromyalgia

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Kenneth S. Casanova
Massachusetts ME/CFS & FM Association
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DISCLAIMER

The Massachusetts ME/CFS & FM Association serves as a clearinghouse for information about Fibromyalgia Syndrome (also known as Fibrositis).

This book is intended to give people ideas as to what is involved in qualifying for some programs which provide disability or other benefits. The book is not intended to cover all programs and is not intended to be a substitute for the advice of a competent attorney. This book reflects an accumulation of opinions and experiences of different individuals and advocates and nothing more. For legal advice it is imperative to consult with an attorney or qualified legal advocate of your own choosing. Further, the law is fluid and what applies in Massachusetts at a particular time may not apply elsewhere and visa-versa. Moreover, what is valid today in this booklet when it goes to press may not be valid after it is published. The Massachusetts ME/CFS&FM Association, Kenneth Casanova, and any and all persons who participated in authoring, contributing to, or producing this booklet assume no responsibility for any use of this booklet by its readers or for any results or consequences of such usage or further, for any other activity which occurs from the reading of the booklet or the application of its content

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HOW TO USE THIS BOOK

The book is very long because there are so many aspects of the Social Security Disability process, and each requires detailed discussion in order that you will be well-informed so that you can make the best decisions possible.

A sick individual will find it difficult to read through this booklet except during times when they are feeling better ; this book is meant to be read in steps according to what you need to know, according to what step of the Social Security process you are on.

Applying for Social Security Disability is often a long-haul process, so take it one step at a time, and learn what you need to at each stage. Just learn at your own pace – or if you have a family member or friend who can help you learn from this book, all the better.

Obviously this book is meant to be comprehensive – so as not to leave out anything that would give you the best chance to win your case.

The book is not meant to be read through entirely. You should use the Table of Contents to find the information you need as follows:

If you want to know if you are potentially eligible to apply, start by reading the Introduction.

If you decide to apply, then you must read the main body of the booklet after the Introduction, as well as Appendix I for ME/CFS; and Appendix III for fibromyalgia. ***Also you should absorb Appendix IV, since it gives you a wealth of information on how to document the illness.*** If you already have an up-to-date and well-documented ME/CFS diagnosis, you may want to skip the section on “Obtaining a ME/CFS Diagnosis.”

It is very important that everyone read, no matter what stage you’re involved in, Appendix I on the **2014 Social Security ME/CFS Ruling** because it’s so important. Also, you must read the Social Security Guidance for providing medical evidence: **“Providing Medical Evidence for Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome”**, and make sure your physician(s) have a copy.

For Fibromyalgia sufferers many sections of this booklet apply generally to fibromyalgia disability applications. There are also sections that apply specifically to FM, particularly the **2012 Fibromyalgia Social Security Ruling** (see Appendix III.)

If you reached the Administrative Law Judge hearing stage for ME/CFS, turn to Appendix I, IV and V. If you’re getting reviewed when you are on Disability, turn to Appendix VIII.

If you are a lawyer and are looking for positive legal precedents for winning ME/CFS or FM Disability claims, see Appendix VII.

If you are applying for disability through your employer, read Appendix IX and Appendix IV. You should also look at the section on Long-Term Employer Disability on our website: <https://www.massmecfs.org/disability>.

You get the idea: **Navigate the booklet by 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 ME/CFS, that it has helped many. I hope it helps you.

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>

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INTRODUCTION

Eligibility for Social Security Disability Programs

There are 2 Social Security disability programs available to ME/CFS patients who are disabled – that is, who are unable to work.

The two programs are:

SSDI - Social Security Disability Insurance

SSI - Supplemental Security Income

To qualify for either or both programs, the disabled individual must meet both the *Financial Eligibility Standards* and the *Disability Eligibility Standard* for each program.

Disability Eligibility Standards for SSDI and SSI

The Disability Eligibility Standard is the same for both programs. The standard is one of total disability, i.e., the person is unable to engage in any substantial gainful activity. What this means is:

The person is unable to do any, work, even part-time sedentary work, on any predictable basis, and this situation has lasted or is expected to last for at least a year:

In addition to meeting this disability standard, the individual must meet the financial eligibility standards for each program. SSDI and SSI have very different financial eligibility standards.

Financial Eligibility Standards for SSDI

An employee under the Social Security retirement age (in 2020: age 66) may qualify for disability benefits. The following family members of employees may also qualify for benefits:

- unmarried son or daughter who is under 18 (19 if in high school)
- an unmarried son or daughter if disabled before age 22
- a spouse who is:
 - age 62 or older, or
 - caring for a child who is under 16 or disabled
- a disabled widow or widower (benefits are payable beginning at age 50)
- a disabled, divorced widow or widower.

An individual may qualify for SSDI without regard to the amount of his own or his family's income or assets. To qualify the applicant must have paid Social Security Payroll Taxes (FICA) at one or more jobs for a specified period of time immediately prior to becoming disabled.

The necessary period of time worked is measured in "quarters" (three months). During each year

you worked, depending on the amount of money you earned, you can accumulate up to 4 quarters.

The amount needed for a work credit changes from year to year. In 2020, for example, you earn 1 credit for each \$1,410 in wages or self-employment income. When you've earned \$5,640, you've earned your four credits for the year.

You qualify for SSDI if you have accumulated the required number of quarters in a specified number of years immediately prior to your date of disability. The required number of quarters and the specified period of years needed in order to qualify for SSDI depend upon the applicant's age at the time of application.

The chart below shows the number of quarters you need and the number of years in which you must have earned them according to your age. (*Again, the specified period refers to the time immediately prior to your becoming disabled.*)

Quarters Needed to Qualify for the SSDI Program

<i>Age</i>	<i>Quarters</i>	<i>Within</i>
<i>16-24</i>	<i>6</i>	<i>3 years</i>
<i>24</i>	<i>8</i>	<i>4 years</i>
<i>25</i>	<i>10</i>	<i>5 years</i>
<i>26</i>	<i>12</i>	<i>6 years</i>
<i>27</i>	<i>14</i>	<i>7 years</i>
<i>28</i>	<i>16</i>	<i>8 years</i>
<i>29</i>	<i>18</i>	<i>9 years</i>
<i>30</i>	<i>20</i>	<i>10 years</i>
<i>31-65</i>	<i>20</i>	<i>10 years</i>

(Reprinted with permission of the Disability Law Center)

Example: You are 35 and you now realize you are no longer able to work at all. The chart shows you must have accumulated 20 quarters. Since you have just become disabled, your ten-year period extends backward from the current date. You became disabled in 2020, so your ten-year period runs from 2010 to 2020. If you earned 20 quarters total during any years over this ten-year period, then you meet the financial qualification standard for SSDI.

To find out if you have earned the required number of quarters in the specified period of years according to your age, you can either set-up an online Social Security account, call Social Security at 1-800-772-1213, or call your local Social Security Office to obtain your Personal Earnings Benefit Statement (PEBES)

If you are one or two quarters short, you may still be able to qualify. You can get in touch with the Association for guidance on this point – or a qualified disability attorney or advocate.

Your date of disability may not coincide with the date you apply for disability. People with ME/CFS are often out of work one or more years before they apply for SSDI and/or SSI. Since you do not accumulate quarters while you are not working (between the time you became disabled and the application date) this period of time out of work may complicate the effort to achieve the required number of quarters for your age.

Therefore, it is important to document that you actually became disabled as close as possible to the date you actually stopped working. By doing so you may not lose quarters. Your date of disability is the date you became no longer able to do any work on any predicable basis. Through proper documentation, you may be able to establish your date of disability for the period of time you were out of work before you actually applied for SSDI. Such “backdating” also allows you to potentially collect benefits retroactively for the period of time you’ve already been out of work.

Example: You have been out of work for 2 years with ME/CFS. You have just now decided you must apply for SSDI. You are 30 years old. So you must have 20 quarters over a period of ten years. It is now 2020. If you became disabled on this date, your 10 year period for accumulating 5 years-worth of quarters is from 2020 back to 2010.

However you stopped working in 2017, having just accumulated 5 years-worth of quarters over the 10 year period 2007-2017. If your date of disability was 2020 you would lose 3 years-worth of quarters and not qualify. However, if you can document that you first became disabled in 2017, you can backdate your application to that date, and therefore can qualify.

The amount of monthly payment received on SSDI is based on your wage history prior to your becoming disabled. On SSDI you also begin receiving Medicare medical insurance starting two years following your date of disability.

Supplemental Security Income (SSI)

Often people who are chronically-ill and disabled have not worked for many years, or have only worked part-time, or even worked at employment where they did not pay Social Security payroll taxes, so they don’t have the “quarters paid” in payroll taxes in order to qualify for SSDI.

For people who don’t have sufficient work credits and are disabled, SSI may be available. However, SSI is a program that has tough income and asset requirements. There is an income ceiling that a person or couple must be below in order to qualify. Income from all sources is considered (except for some small exemptions). Income from a spouse is considered income. There is also a maximum asset requirement – you cannot have more than \$2,000 in assets if single and \$3,000 if married.

Financial Eligibility Standards for SSI

The chart below summarizes the *maximum* assets and property you may have and still be eligible for SSI.

Maximum Property Value That a Disabled Person Can Own and Still Be Eligible for the SSI Program		
<i>Property</i>	<i>Maximum Value</i>	<i>Conditions</i>
Savings accounts and other assets (excluding items below)	\$2,000 \$3,000	For a single person. For a married couple.
Car	-	A single car's value is unlimited within reason. (Not a luxury' car such as a Cadillac or Jaguar.) A second car's value is considered as an asset.
House	-	Unlimited, as long as you live in it.
Furniture and other household or personal property	-	Unlimited, as long as individual item's value is not over \$500. (Remember the value of goods is the smallest amount you could get if you tried to sell them.)
Life Insurance	-	Life insurance is considered an asset. Term insurance is not taken into account.
Burial insurance	\$1,500	The policy has to specify the proceeds can only be to pay burial expenses of the insured individual.

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

The above figures are subject to change. You can call the Disability Law Center at (617) 723-8455 for the correct current figures. You may want to get additional advice on calculating your assets. These figures will be significantly different for individuals taking part in the Plans for Achieving Self-Support program (PASS). (See Addendum I for more details.)

To qualify for SSI, your monthly income (plus, if married, your spouse's income which counts toward your income) must fall below (with certain deductions) the SSI monthly income that you would receive. The monthly SSI payment is the same for all recipients in Massachusetts, depending on an individual's living arrangements. (Monthly SSI payments vary by state as will the income qualifications.)

In 2019 for a single person living alone, the SSI monthly flat payment was approximately \$885.39. (The payment may be less for a person living in a shared living situation.) For a member of a couple, the income payment/threshold was \$652.63 in 2018. (Check with your Social Security office for an exact figure.) If your monthly income is substantially above these figures, you would not be eligible.

If you qualify for SSI, you will receive Medicaid (Mass. Health) immediately – no 2-year waiting period as for Medicare. You probably will also qualify for food stamps and fuel assistance.

SSI for children: If your child has ME-CFS, he or she is also eligible for supplemental security income (SSI). (Social Security must consider the parents' income and assets to decide if the child qualifies.) The child must present evidence of disability and may be asked to be examined at the expense of Social Security. Parents can apply for the child by calling or going to the local Social Security Office. These individuals who qualify for SSI would also qualify for medical coverage. In Massachusetts this is automatic. In some states you must sign up for this coverage. Medicaid programs pay for medical examinations, dental care and vision care.

If an individual is eligible for SSDI, it is possible that the monthly SSDI payment will be below the state's standard SSI payment amount. This may occur because the applicant's wages prior to becoming disabled were low - especially if the applicant was working part-time or infrequently. In this case, the applicant may qualify for both SSI and SSDI if the applicant otherwise meets SSI's financial eligibility standards. (If in doubt, apply for both programs.) If the applicant is eligible for both programs and the SSDI amount is less than the SSI amount, the SSDI check will be supplemented by SSI up to the SSI payment amount.

You should not apply for SSDI or SSI while you are continuing to receive unemployment compensation.

***Emergency Aid to the Elderly, Disabled
& Children Program (EAEDC)***

The approval process for SSDI or SSI can take up to a year or longer. Applicants who have very few assets and negligible income may need to apply for EAEDC while their Social Security application is being processed. Applications for EAEDC are available at your local welfare department -now called the Department of Transitional Assistance.

The EAEDC program succeeds the old General Relief program. As part of the application, your doctor must fill out a medical form documenting your ME/CFS diagnosis and your inability to work. Have your doctor use the Social Security medical diagnosis standards for ME/CFS plus the functional disability incapacity standards reviewed below.

If you are approved, the EAEDC program will provide monthly cash assistance plus Medicaid medical insurance. (The cash assistance amount is very low.)

If you would like information on the EAEDC program or wish to apply, google the program or call your local Office of Transitional Assistance.

If you find you are having difficulty applying for the EAEDC program or if you have been denied benefits, you can receive assistance through your local legal services office.

Food Stamps and Fuel Assistance:

If you have a low income and limited assets, either while you are awaiting Social Security benefits or after you have been awarded benefits, you may be eligible for food stamps. You can use a monthly grant of food stamps to buy food. In Massachusetts call your local Transitional Assistance Office to find out about your food stamp eligibility and how to apply.

Again if you are of limited means, you may be eligible for fuel assistance during the winter months to help you pay for your heating costs.

For both programs you can also use your search engine.

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>.

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.

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

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>

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/1SG7hJTCSDrDHqvioPMq-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* exclude 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 your doctor's treatment notes 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.

APPENDIX I

The 2014 Social Security Ruling for the Evaluation of CFS Disability Claims

The following is a comprehensive review and evaluation of the new Social Security Ruling for the evaluation of medical evidence and work capacity in ME/CFS claims. Understanding and use of this Ruling is essential for anyone pursuing a ME/CFS Social Security Disability Claim or Review – including those assisting them, for example health care practitioners and attorneys/advocates. The full Ruling can be accessed at:

https://www.ssa.gov/OP_Home/rulings/di/01/SSR2014-01-di-01.html

This review and evaluation is extensive because its importance is in the detail, and in understanding the detail, and its application.

We urge patients and their families needing Social Security benefits to slowly read and digest the following review. The Ruling does not use the term ME/CFS – uses the term CFS instead; so in parts quoted, we will leave the terms as they are.

We hope to shortly publish a shorter summary for use by physicians for medical documentation, but the summary will not be a substitute for a full understanding of the Ruling.

Disclaimer: This review and evaluation of the Ruling contains the opinions of the author as to how claimants, physicians, attorneys and others might utilize the policies and language in the Ruling in the effort to document CFS disability claims.

While these opinions are based on the language of the Ruling, as well as extensive experience with the Social Security disability process, there is no way to accurately know in what manner the Social Security Administration and associated agencies will, in practice, implement the new Ruling. The Ruling will likely not be applied or interpreted uniformly at all administrative levels or geographic areas of evaluation. Some elements of the Ruling are likely to be given more emphasis than others; nor is the Ruling expected to remain static in its application over time. In regard to the documentation of medical signs, symptoms, medical tests and functional evaluation, it is only possible, at this time, to make reasonable inferences from the Ruling's language as to how CFS claims might be evaluated; however, these inferences cannot be expected to predict how the different signs, symptoms and tests will actually be evaluated. Therefore, Kenneth Casanova, other authors/contributors of this booklet, and the Massachusetts ME/CFS & FM Association assume no responsibility for any use of this document by its readers for any results or consequences of such usage or further, for any other activity which occurs from the reading of the document or the application of its content. This document is not intended to be a substitute of the advice of a competent attorney who is well-versed on the Ruling and the disability evaluation process. For legal advice it is imperative to consult with such an attorney or qualified legal advocate of the reader's own choosing.

The New Ruling:

On April 3, 2014, the Social Security Administration issued a critical new Ruling: **SSR 14-1p “Titles II and XVI: Social Security Rulings: Evaluating Claims Involving Chronic Fatigue Syndrome.”** This new Ruling now establishes the guidance by which Social Security evaluates ME/CFS disability claims and reviews for both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). (See below for the relevancy of the illness names to this Ruling.)

The Ruling is “...binding on all components of the Social Security Administration.” This new Ruling replaces the former CFS evaluation Ruling issued in 1999 (SSR-99-2p). The new SSR provides guidance on how evidence is properly developed to establish that a person has a medically-determinable impairment of chronic fatigue syndrome and how the impairment is evaluated in determining whether the claimant is sufficiently disabled to qualify for benefits.

The Ruling requires that for a person to be found disabled “... he or she must be unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s)(MDI) which...can has lasted or can be expected to last for a continuous period of not less than 12 months.”

The medical impairment must be established “by medical evidence that consists of signs, symptoms, and laboratory findings...” Therefore, “a claimant may not be found disabled on the basis of a person’s statement of symptoms alone.” Hence, the Ruling sets forth the medical signs and laboratory findings by which a case of CFS may be determined.

In the 1999 Ruling, the SSA used only the 1994 Centers for Disease Control case definition as the basis for determining a case of CFS and for establishing its medically determinable signs, symptoms and laboratory findings.

The new Ruling primarily adapts the 1994 CDC definition, but also uses “to some extent” the newer 2003 Canadian ME/CFS Criteria as well as the 2011 ME International Consensus Criteria (Adult and Pediatric). As a result of recognizing the two more recent diagnostic Criteria, the Ruling includes a broader and more characteristic listing of signs, symptoms, and laboratory tests for CFS – thereby allowing claimants and their physicians to better, and with less difficulty, document and validate the illness.

Interestingly, the Ruling states: “As mentioned we include ME as a subtype of CFS. When we refer to CFS in this SSR, we include ME.” Note: Because the Ruling primarily adopts the 1994 CFS Case Definition, claimants and their doctors would be wise to include CFS as a diagnosis, in addition to a diagnosis of ME, if applicable.

Summary and Evaluation of Ruling:

The following will be a summary of the Ruling. We suggest that the applicant, or anyone assisting the applicant, thoroughly review the Ruling itself at

http://www.ssa.gov/OP_Home/rulings/di/01/SSR2014-01-di-01.html

The Ruling is divided into six major sections: “I. What is CFS?”; “II. How does a person establish an MDI of CFS?”; “III. How do we document CFS?”; “IV. How do we evaluate a person’s statements about his or her symptoms and functional limitations?”; “V. & VI. How do we find a person disabled on an MDI of CFS?; How do we consider CFS in the sequential evaluation process?”

What is CFS? In determining a case of CFS, the first portions of this section (A. and B1.) largely follow the 1994 CDC definition, the text of which can be found on page 3 of the Ruling. “The CDC and other medical experts characterize CFS, in part, as a syndrome that causes prolonged fatigue lasting 6 months or more, resulting in a substantial reduction in previous levels of occupational, educational, social or personal activities.”

Using the CDC definition, the Ruling makes clear that a “physician should make a diagnosis of CFS only after alternative medical and psychiatric causes of chronic fatiguing illness have been excluded.”

Major hallmark symptom: 1) “...clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; cannot be explained by another physical or mental disorder; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities; “

Additional symptoms of CFS

Diagnostic symptoms: “...the concurrence of four or more of the following symptoms, all of which:

must have persisted or recurred during 6 or more consecutive months of illness and

must not have predated the fatigue:

post-exertional malaise lasting more than 24 hours

self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities;

sore throat;

tender cervical or axially lymph nodes;

muscle pain,
multi-joint pain without joint swelling or redness;
headaches of a new type, pattern, or severity;
waking unrefreshed”

An applicant’s physician must document and validate the CFS diagnosis by using the CDC definition and when able, also by the CCC and ICC definitions. Diagnosis is made by symptoms, medical signs and medical/laboratory tests. Hence, any of the above diagnosis symptoms should be included.

However, in section B2., “Other Symptoms”, the Ruling expands the list of CFS symptoms as more recently outlined in the Canadian Criteria and the International Consensus Criteria – in addition to the CDC symptoms

“Other Symptoms. Within these parameters, the CDC case definition, CCC, and ICC describe a wide range of other symptoms a person with CFS may exhibit:

- Muscle weakness;
- Disturbed sleep patterns (for example, insomnia, prolonged sleeping, frequent awakenings, or vivid dreams or nightmares);
- Visual difficulties (for example, trouble focusing, impaired depth perception, severe photosensitivity, or eye pain);
- Orthostatic intolerance (for example, lightheadedness, fainting, dizziness, or increased fatigue with prolonged standing);
- Respiratory difficulties (for example, labored breathing or sudden breathlessness);
- Cardiovascular abnormalities (for example, palpitations with or without cardiac arrhythmias);
- Gastrointestinal discomfort (for example, nausea, bloating, or abdominal pain); and
- Urinary or bladder problems (for example, urinary frequency, nocturia, dysuria, or pain in the bladder region).”

As will be seen later, the inclusion of these common elements of ME/CFS allows for an increased ability to provide medical evidence of the illness in terms of the necessary documentation of medical signs and laboratory testing.

In the last subsection 3 is the following text:

“Co-occurring Conditions. People with CFS may have co-occurring conditions, such as fibromyalgia (FM), myofascial pain syndrome, temporomandibular joint syndrome, irritable bowel syndrome, interstitial cystitis, Raynaud's phenomenon, migraines, chronic lymphocytic thyroiditis, or Sjogren's syndrome. Co-occurring conditions may also include new allergies or sensitivities to foods, odors, chemicals, medications, noise, vibrations, or touch, or the loss of thermostatic stability (for example, chills, night sweats, or intolerance of extreme temperatures).” Again, the new Ruling (based on the more recent ME/CFS and ME definitions) includes many more of the essential elements of the illness that increase the physician’s ability to provide medical documentation. Many of these “co-occurring conditions” are essential symptoms of ME/CFS and their documentation adds to diagnostic clarity. Notably, multiple sensitivities and loss of thermostatic stability have for years been known to patients and educated clinicians, but are now just being fully recognized.

Other conditions that may explain symptoms similar to CFS: The Ruling reads : “Additionally, several other disorders (including, but not limited to FM, multiple chemical sensitivity, and Gulf War Syndrome, as well as various forms of depression, and some neurological and psychological disorders) may share characteristics similar to those of CFS. When there is evidence of the potential presence of another disorder that may adequately explain the person's symptoms, it may be necessary to pursue additional medical or other development. As mentioned, if we cannot find that the person has an MDI of CFS but there is evidence of another MDI, we will not evaluate the impairment under this SSR. Instead, we will evaluate it under the rules that apply for that impairment.”

Therefore, in documenting a diagnosed case of CFS, the treating physician(s) should not only document any co-occurring conditions, but also should be sure to, if possible, clearly differentiate CFS from other conditions that may share over-lapping symptoms.

II. How does a person establish ME/CFS as a medical impairment?

The person making a Social Security claim through medical evidence provided by a physician must document that they have a *medically-determinable impairment* – that is a medically recognized, properly diagnosed illness – in this case: ME/CFS.

** “A licensed physician (a medical or osteopathic doctor) is the only acceptable medical source who can provide such evidence.” (emphasis added)**

Additional supporting evidence can be provided by other health care practitioners and other lay people, but without the primary medical evidence provided by a physician, the case will fail.

The Ruling goes on to note:

“We cannot rely upon the physician's diagnosis alone. The evidence must document that the physician reviewed the person's medical history and conducted a physical exam. We will review the physician's treatment notes to see if they are consistent with the diagnosis of CFS; determine whether the person's symptoms have improved, worsened, or remained stable; and establish the physician's assessment of the person's physical strength and functional abilities.”

Despite the fact that the CDC definition allows for physician diagnosis based on symptoms and exclusion of other illnesses and conditions, the Ruling requires that for the purposes of establishing disability: *“there must also be required medical signs or laboratory findings.”*

What are the medical signs?:

- A. “For the purposes of Social Security disability evaluation, one or more of the following medical signs clinically documented over a period of at least 6 consecutive months help establish the existence of an MDI of CFS:
- Palpably swollen or tender lymph nodes on physical examination;
 - Non-exudative pharyngitis;
 - Persistent, reproducible muscle tenderness on repeated examinations, including the presence of positive tender points; or
 - Any other medical signs that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record. For example, the CCC and ICC explain that an acute infectious inflammatory event may precede the onset of CFS, and that other medical signs may be present, including the following:
 - Frequent viral infections with prolonged recovery;
 - Sinusitis;
 - Ataxia;
 - Extreme pallor; and
 - Pronounced weight change.”

This short list is not strictly limited: note the reference, “*Any other medical signs that are consistent with medically accepted clinical practice and consistent with the other evidence in the record.*”

Hence, a physician well-educated and experienced in ME/CFS practice may be able to provide additional signs consistent with CFS depending on the individual case. It should be clearly understood that CFS disability documentation is not necessarily limited to the signs specifically listed. Many patients may not have one or more of the listed signs, but will have others known to be consistent with CFS.

The inclusion in the signs of frequent viral infections with prolonged recovery is a new recognition of another hallmark of the illness; so also is the new inclusion of an “acute infectious inflammatory event [that] may precede the onset of CFS”.

The new acceptance of these signs is a very distinct improvement in Social Security’s criteria and recognition of the illness.

Again, one or more physicians must fully document the medical signs, and this should be done over sequential office visits.

All of these signs, including their severity and chronicity, should be carefully documented in the doctor(s)’ notes and medical reports.

Laboratory Findings: Subsection C outlines acceptable laboratory findings as follows:

A. “At this time, we cannot identify specific laboratory findings that are widely accepted as being associated with CFS. However, the absence of a definitive test does not preclude our reliance upon certain laboratory findings to establish the existence of an MDI in people with CFS. While standard laboratory test results in the normal range are characteristic for many people with CFS, and they should not be relied upon to the exclusion of all other clinical evidence in decisions regarding the presence and severity of an MDI, the following laboratory findings establish the existence of an MDI in people with CFS:

- An elevated antibody titer to Epstein-Barr virus (EBV) capsid antigen equal to or greater than 1:5120, or early antigen equal to or greater than 1:640;
- An abnormal magnetic resonance imaging (MRI) brain scan;
- Neurally-mediated hypotension as shown by tilt table testing or another clinically accepted form of testing; or
- Any other laboratory findings that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record (for example, an abnormal exercise stress test or abnormal sleep studies, appropriately evaluated and consistent with the other evidence in the case record).”

Essentially, these tests are the same as those stated in the 1999 Ruling.

Comments on these laboratory tests:

The EBV titer threshold numbers are so high as to have only occasional diagnostic purpose for selecting cases of ME/CFS. Most patients may have above average titers, but not in the stated range. Above average numbers for EBV or other herpes viruses should be included as indicative of ME/CFS, especially if tests show a viral reactivation.

Only in a percentage of ME/CFS patients will have MRI brain scans that show abnormalities: punctate white spots. However, a patient showing abnormalities on one scan will often on a

second scan show perfectly normal results. Therefore, such scans are likely diagnostic only in a minority of cases. Many patients, however, not showing diagnostic results on other tests may feel compelled to obtain an MRI in an effort to document their illness. MRIs are costly, and without insurance, beyond the reach of many patients. Moreover, only a neurologist familiar with the relation of punctate white spots to CFS would usually be able to provide the likely diagnostic connection to CFS.

A proportion of ME/CFS patients have neurally-mediated hypotension. Tilt-table tests are expensive and may not be reimbursable. Patients seeking the test would have to receive the test from a physician following protocols known to be diagnostic for CFS patients. A tilt-table test performed by a tester unfamiliar with ME/ CFS may or may not be of value.

The Ruling appears to allow for an alternative test (“or other clinically-accepted form of testing”) which might include the "poor man's tilt-table" : the taking of blood pressure sequentially -- lying down, then immediately after standing, and then 3 minutes later, standing again. Such a test performed by a ME/CFS-informed physician could be of value if a standard tilt-table test is not available.

Sleep studies certainly may show abnormalities in ME/CFS patients. However, the ME/CFS diagnostic value of the sleep testing for Social Security will depend on the tester’s knowledge of abnormal sleep architecture in the illness.

Exercise stress tests performed on ME/CFS patients often appear normal during and immediately after the test itself – but abnormal effects may only appear as severe insufficiency of recovery in the days following the testing. Therefore, a tester familiar with CFS will document the “recovery period” (or lack of it) as an integral part of the test.

Hence, some of these lab tests listed will be difficult for most ME/CFS patients to obtain and if not knowledgeably performed may not be diagnostic in a substantial percentage of cases. A patient should seek out a tester, if available, who can document actual post-exertional malaise.

However, the current Ruling includes additional important text relating to:

“Additional signs and laboratory findings:

Because of the ongoing research into the etiology and manifestations of CFS, the medical criteria discussed above are only examples of physical and mental signs and laboratory findings that can help us establish the existence of an MDI; they are not all-inclusive. As medical research advances regarding CFS, we may discover additional signs and laboratory findings to establish that people have an MDI of CFS. For example, scientific studies now suggest there may be subsets of CFS with different causes, including viruses such as Human Herpesvirus 6. *Thus, we may document the existence of CFS with medical signs and laboratory findings other than those listed above provided such evidence is consistent with medically accepted clinical practice, and*

is consistent with the other evidence in the case record .(emphasis added).”

Therefore, physicians and patients should not be limited by the specific laboratory findings outlined. Abnormal antibody findings or the continuing presence of other infectious agents should be documented.

Furthermore, it is well-established among ME/CFS knowledgeable clinicians that certain abnormalities in blood work can help in the confirmation of CFS.

Dr. Anthony Komaroff, a leading specialist in ME/CFS, cites the following laboratory abnormalities as supportive of a CFS diagnosis (while these are not listed in the Ruling, they should be documented):

Laboratory Abnormalities and Chronic Viral Fatigue Syndrome (CFS)

Mild leukopenia (3000-5000/mm)
Moderate monocytosis (7%-15%)
Relative lymphocytosis (>40%)
Atypical lymphocytosis (1%-20%)
Slight elevation in SGOT and SGPT
Erythrocyte sedimentation rate unusually low (0-4mm)
Partial reduction in immunoglobulins
Circulating immune complexes (low levels)
Increased CD4/CD8 ratio

Also, very important: In Section I, “What is CFS”, B2, “Other Symptoms”, discussed above, the Ruling introduces new elements of the illness identified in the Canadian and International Consensus Criteria. Many of these symptoms can be identified objectively as medical signs or in laboratory testing. If the diagnosing physician identifies such symptoms and conditions, and s/he can document their signs and obtain identifying lab or other testing, then such positive documentation should be provided to Social Security. Such conditions, cited in the Ruling, include:

“Muscle weakness; Visual difficulties (for example, trouble focusing, impaired depth perception, severe photosensitivity, or eye pain); Respiratory difficulties (for example, labored breathing or sudden breathlessness); Cardiovascular abnormalities (for example, palpitations with or without cardiac arrhythmias); Gastrointestinal discomfort (for example, nausea, bloating, or abdominal pain); and Urinary or bladder problems (for example, urinary frequency, nocturia, dysuria, or pain in the bladder region).”

“E. *Mental limitations*” is the next subsection, and reads as follows: “Some people with CFS report ongoing problems with short-term memory, information processing, visual-spatial difficulties, comprehension, concentration, speech, word-finding, calculation, and other symptoms suggesting persistent neurocognitive impairment. When ongoing deficits in these

areas have been documented by mental status examination or psychological testing, such findings may constitute medical signs or (in the case of psychological testing) laboratory findings that establish the presence of an MDI. When medical signs or laboratory findings suggest a persistent neurological impairment or other mental problems, and these signs or findings are appropriately documented in the medical record, we may find that the person has an MDI.”

ME/CFS patients and their physicians must understand both the assistance provided by this section, but also be acutely aware of its pitfalls – so as not to be misguided into undermining CFS illness diagnosis. The above findings fall into two different diagnostic categories: “*neurocognitive impairments*” and “*mental problems*”.

Neurocognitive impairments, as listed, are a hallmark of the biological aspects of ME/CFS and are suffered by a high proportion of patients. When they are documented by proper testing the impairments provide important laboratory documentation of the illness. However, despite the text of the Ruling, neurocognitive impairments in CFS are best determined by “neuropsychological testing” not “psychological testing.”

Very important: Neuropsychological testing will only be diagnostically helpful in the hands of an experienced tester familiar with ME/ CFS. In the wrong and inexperienced hands such testing may falsely indicate a psychological disorder. Neuropsychological testing from an experienced CFS tester is probably not easily available in many parts of the U.S. Such testing is also relatively expensive. Yet obtaining the proper neuropsychological testing may be one of the best ways, under these guidelines, to provide a positive laboratory finding.

Despite some prevailing opinion that ME/CFS claimants must obtain neuropsychological testing in order to have a chance at obtaining Social Security benefits, the fact is that such opinion is both incorrect and may lead to harmful results if the testing is done by an tester inexperienced with ME/CFS.

Many, many ME/CFS patients (likely in the thousands) have been approved for benefits without having had neuropsychological testing. An ME/CFS patient who receives testing from an unreliable tester may receive an opinion that the neurocognitive deficits are based on a psychological disorder – thereby undermining the ME/CFS diagnosis. If a patient does not know of an experienced tester familiar with ME/CFS, it would be more prudent not to be tested.

Mental status examination:

The text of the Ruling mentions a “mental status examination” along with psychological testing as a method of documenting the types of neurocognitive deficits listed in the text, e.g. short-term memory, information processing, word-finding, calculation, etc.

The 1994 CDC case definition describes a mental status examination in the following terms:

“A mental status examination to identify abnormalities in mood, intellectual function, memory, and personality. Particular attention should be directed toward current symptoms of depression or anxiety, self-destructive thoughts, and observable signs such as psychomotor retardation. Evidence of a psychiatric or neurological disorder requires that an appropriate psychiatric, psychological, or neurological evaluation be done.”

However, the CDC diagnostic criteria states that the mental status examination is performed by the diagnosing physician – and therefore does not necessarily require examination by a psychiatrist or other mental health professional.

The term, "mental status examination" does not refer to any standardized or formal test or procedure of evaluation; instead, the term refers to a fairly informal and basic assessment of the presence of any disorders or symptoms listed just above; certainly, what constitutes a "mental status examination" will vary among examining physicians. The CDC definition indicates that if evidence of a psychiatric or neurological disorder is found, then a further psychiatric, psychological, or neurological evaluation would be required.

Here ME/CFS patients and the physicians assisting in documentation of their CFS disability must be knowledgeable. Physicians who note symptoms of depression or anxiety must determine initially if such symptoms/conditions are largely determined by the patient's natural reaction to a serious chronic physical illness. Such depressive symptoms are known as *secondary or reactive depression*. In documenting these symptoms, the physician should carefully and explicitly note their secondary nature and the CFS itself as their causative factor. By so doing, the physician will not undermine a diagnostic finding of CFS.

In some cases it is quite possible for a person to suffer both from ME/CFS and additionally a primary – not secondary – psychiatric illness. For instance, a person with primary depression could also have MS. In such a case, the physician or psychiatrist must absolutely document that the person has CFS independently from the psychiatric illness.

****Important Caution: If a patient is also on, or applying for long-term disability insurance, he or she should carefully examine their disability policy. Different policies use different language relating to the effect of depression, anxiety, or other mental impairments on long-term disability eligibility.*

Some policies state that if a mental impairment simply “contributes to” the physically-based CFS disability, then the patient will be ineligible for long-term disability insurance or the benefits will be limited to a relatively short time period.

If this language is in the disability policy, then the physician documenting CFS for Social

Security should clearly note that the depression, anxiety, etc. does not, in any way, contribute to the disability – that the disability and the inability to work is entirely the result of the CFS – in other words, if the person did not have CFS s/he would be able to work.

For the patient who is applying for, or already receiving, both LTD and Social Security benefits, it is critical to utilize a single knowledgeable attorney who is familiar with ME/CFS, as well as being competent in representation for both Social Security and LTD benefits. As just discussed, how the person is represented for Social Security can have profound effects on their LTD eligibility. Having one attorney make sure the representation for both is coordinated is essential. The patient should not accept an insurance company's offer to provide an attorney to represent them before Social Security. Such representation can provide the insurance company with information that could affect eligibility for LTD benefits. However, if the insurance company is willing to pay for own lawyer – and your lawyer agrees not to provide your information to the insurance company – then this is an offer that could well be considered.

If the physician feels s/he is not qualified to make a proper diagnosis of CFS in the light of the patient's mental/emotional symptoms, then a referral might be made to a mental health professional familiar with ME/CFS – so that a possible misdiagnosis of a psychiatric illness to the exclusion of CFS will not be made. Also, if a treating physician judges that depression or anxiety secondary to CFS is sufficiently serious in itself and requires treatment, then referral should be made to a mental health professional who can correlate mental health treatment to ME/CFS.

III. How Do We Document CFS:

What type and form of medical documentation is required by Social Security in the new Ruling?

The Ruling states:

“In cases in which CFS is alleged, we generally need longitudinal evidence because medical signs, symptoms, and laboratory findings of CFS fluctuate in frequency and severity and often continue over a period of many months or years.”

[“Longitudinal evidence” means that which is collected and documented over multiple office visits over a reasonably substantial period of time.]

“Longitudinal clinical records reflecting ongoing medical evaluation and treatment from the person's medical sources, especially treating sources, are extremely helpful in documenting the presence of any medical signs or laboratory findings, as well as the person's functional status over time. *The longitudinal record should contain detailed medical observations, information about treatment, the person's response to treatment, and a detailed description of how the impairment limits the person's ability to function.*” (Emphasis added.)

If the person has been ill for more than 12 months prior to application, the Ruling states:

“...Generally we will request evidence from your medical sources for the 12 month period preceding the month of application unless there is reason to believe that development of an earlier period is necessary...”

Also: “When the alleged onset of disability secondary to CFS occurred less than 12 months before adjudication, we must evaluate the medical evidence and project the degree of impairment severity that is likely to exist at the end of 12 months. Information about the person's treatment and response to treatment, as well as any medical source opinions about the person's prognosis at the end of 12 months, helps us decide whether to expect the MDI to be of disabling severity for at least 12 consecutive months.”

Comments: It is the Patient's responsibility to work with his/her physician(s) to develop and maintain a detailed and complete record in which entries are made at sufficiently frequent periodic intervals:

The Ruling requires documentation of medical signs, symptoms, laboratory findings and observations as to how the patient's illness over time has limited and will limit his/her ability to function over time. The Ruling is clear that the doctors’ office notes, record, and charts are primary evidence.

Most of us when we first become ill never imagine that at some point we may need to apply for disability, whether it be Social Security or through our employer.

Nevertheless many ME/CFS patients, at some point, find that they must seek disability benefits. Therefore, especially if a patient is considering applying, and also if a patient is already receiving benefits (anticipating a review), he or she must alert and actively work with his/her physicians to build a comprehensive clinical record that records each and every medical sign, symptom and laboratory result during or following each office visit.

The Ruling makes clear that prior to or during an application or review period, a 12 month consecutive clinical record is needed. Therefore, anticipating or during such periods, patients must make efforts to visit their doctors frequently (6-8 weeks) in order to build the necessary record and be in the best position to document their illness. During this period, patients should discuss with their physicians which lab tests would be appropriate for the documentation of their CFS.

After a successful application or review, patients should maintain ongoing examinations/follow-up with their physicians (4-6 months) in order to maintain a current and ongoing record in anticipation of reviews. Too many ME/CFS patients receiving disability do not see their physicians for long periods of time, often because no new or specific treatments are offered. Then when a review occurs there is no current medical documentation.

Also, very important: While the Ruling emphasizes the 12 month period prior to application or

review, the illness in many ME/ CFS patients has lasted at least several years prior to application, if not longer. In these cases, it is crucial to provide as a full medical record as possible to Social Security including: the nature of onset, the development and progression of the illness and its symptoms (which may change over time), including their severity. Also, there should be documentation of various treatments and treatment outcomes. The full picture of an illness like Me/CFS can best be documented over its full course. Such documentation adds weight and authenticity to the disability application.

Evidence from medical sources other than physicians, and from non-medical sources:

“In addition to obtaining evidence from a physician, we may request evidence from other acceptable medical sources, such as psychologists, both to determine whether the person has another MDI(s) and to evaluate the severity and functional effects of CFS or any of the person's other impairments.” Also, “Under our regulations...we may also consider evidence from medical sources we do not consider ‘acceptable medical sources’ to help evaluate the severity and functional effects of the impairment.” This might include an ongoing chiropractor, naturopath, etc.

“We may also consider information from nonmedical sources. This information may also help us assess the person's ability to function day-to-day and over time. It may also assist us in assessing the person's allegations about symptoms and their effects (see section IV below). Examples of nonmedical sources include:

- Spouses, parents, siblings, other relatives, neighbors, friends, and clergy;
- Past employers, rehabilitation counselors, and teachers; and
- Statements from SSA personnel who interviewed the person.”

How does Social Security evaluate various treating physicians’ medical documentation of the patient’s impairment(s)?

The Ruling reads: “We consider the nature of the treatment relationship between the medical source and the claimant...If we find that a treating source’s medical opinion regarding the nature and severity of a person’s impairment(s) is well-supported by medically acceptable clinical and laboratory diagnostic techniques, and the opinion is not inconsistent with other substantial evidence in the case record, we will give it controlling weight.”

If there is conflicting medical evidence in the claimant’s record, Social Security “may seek clarification of any such conflicts in the medical evidence first from the person’s treating or other medical sources...”

If there is insufficient medical evidence to determine disability, Social Security may seek further evidence from treating or other sources; additional existing records may be asked for; more information may be requested from the claimant or others; Social Security may request the claimant undergo a consultative examination by an independent examiner of their own

choosing.”

(Note: The claimant must accept and attend such an examination or Social Security may deny benefits. Hence it is important to provide sufficient evidence from a physician(s), when possible, to avoid a consultative examination.)

How is a person with ME/CFS found to be disabled?

There is a sequential process in making a finding on whether a person with ME-CFS is disabled. “In this process, once we establish a medically-determinable impairment of CFS, we must establish the severity of the impairment(s). We determine the severity of the impairment(s) based on the totality of medical signs, symptoms, and laboratory findings, and the effects of the impairments, including any related symptoms, on the person’s ability to function.”

Step 1: “We will consider the person’s work activity. If a person with CFS is doing substantial gainful activity, we find that he or she is not disabled.”

Comment: “Substantial gainful activity” in relation to ME/CFS is ill-defined. Based on our experience with scores of ME/CFS claims, and advice from a number of experienced attorneys, any patient working for an even limited number of hours at the time of application risks a finding of performing substantial gainful activity. Limited part-time hours, say 8-10 hours a week may or may not be considered substantial gainful activity depending on the type of work and, to an extent, the claimant’s past work experience. Therefore, while applying, it is generally best not to be employed, based on our experience. If a person must work, it should be generally less than 8 hours per week, and at a job that requires very little effort. Still, to do so, may jeopardize a disability application. After an application is approved, there is a greater allowance for work.

Step 2: There must be a finding that the person has CFS (as well as any other conditions) as a medically-determinable impairment (MDI) which would reasonably cause a person’s symptoms. Moreover, this step also involves determining whether the person’s impairment is “severe”.

In this step there is an evaluation of the intensity and persistence of the person’s symptoms in order to determine the “extent to which they limit the person’s capacity for work... Once a finding is made that the individual’s CFS meets the duration requirement [see above], a determination is made whether the fatigue, pain, neurocognitive symptoms, or other symptoms cause a limitation or restriction, and whether they have more than a minimal effect on a person’s ability to perform basic work activities, [if so] we must find that the person has a ‘severe’ impairment.”

Step 3: There is a Social Security Listing of medical impairments that are considered necessarily severe. CFS in itself is not considered necessarily severe and is not on the “Listing of Impairments”. However in each CFS case the severity of impairment may be compared to a Listing to determine if there is an equivalency of severity. “Further in cases in which a person

has psychological manifestations related to CFS, we must consider whether the person's impairment meets or equals the severity of any impairment in the mental disorders listing." This regulation has in the past often been used by attorneys to take the patient "off the grid" (see below) in order to make acceptance of the CFS claim less difficult – in order to create an "equivalency". This approach can avoid having to go to steps 4 and 5 of an evaluation of the person's *residual functional capacity (RFC)*. However, a finding of equivalency in cases of CFS is infrequent and most claims "advance" to steps 4 and 5 to determine individual functional capacity.

Steps 4 and 5: When CFS does not demonstrate a Listing equivalence there must be an assessment of the person's residual functional capacity – that is their ability to work. Ability to work means the person is unable to do any work, even part-time sedentary work on a predictable basis. In other words, if a person could do 4 hours today and 4 hours tomorrow of light work, but then would be sick for a week or more, then they could not work on a predictable basis and would be considered disabled.

"In assessing RFC, we must consider all the person's impairment related symptoms and how such symptoms may affect functional capacities...we must determine that the person's impairment(s) precludes the performance of past relevant work (or if there was no past relevant work). If we determine that the person's impairment precludes performance of past relevant work, we must make a finding about the person's ability to perform other work. We must apply the usual vocational considerations in determining the person's ability to perform other work."

"Also, in attempting to evaluate the functionally limiting effects of symptoms: "...we consider all the evidence in the case record, including the person's daily activities; medications or other treatments the person uses, or has used, to alleviate symptoms; the nature and frequency of the person's attempts to obtain medical treatment for symptoms..." Hence the patient and treating physician(s) should document these types of evidence in the continuing medical record.

The Ruling also notes: That "statements by other people about the person's symptoms..." may be used. These could be statements by other types of professionals or work supervisors, etc. Therefore, in preparing medical documentation, the person's treating physician(s) must enter into their treatment notes and disability reports, *the chronicity and severity of the patient's symptoms over time, as well as how the symptoms may objectively limit the person's functionality and ability to work.*

The documentation of a person's residual functional capacity is just as critical as the documentation of the CFS diagnosis and severity. It is recommended that the physician or other professional assess and document the person's lack of capacity to carry-out activities of daily living (ADL), their lack of ability to carry-out basic work functions: deficits of concentration, memory, sustaining physical and cognitive activity, carrying out basic physical activities: such as walking, standing, carrying more than very light weights, etc.

Continuing Disability Reviews: “In those cases in which we find that a person is disabled based on CFS, we will schedule an appropriate continuing disability review. For this review, we take into account relevant individual case facts, such as the combined severity of other chronic or static impairments and the person's vocational factors.”

In our experience, Disability Reviews should entail complete documentation of the illness, especially for the 12 months preceding the Review, but also for the period since benefit approval or a preceding review. Please see the Appendix in this booklet on Reviews.

This ends the review and explanation of the new Ruling.

Ruling footnotes:

The extensive footnotes to the Ruling should be important, over time, to the further recognition of CFS/ME, to a broadening of the acceptable medical signs and laboratory tests, and for attorneys adjudicating cases before Administrative Law Judges. Attorneys should review these footnotes.

Of interest to patients and their doctors, here is a quick summary of important footnotes:

(1) The policies of the Ruling apply to claims of children (under 18).

(12) “In children, symptoms may progress more gradually than in adolescents or adults.”

(16) “In addition, generalized pain and neurological symptoms (for example, headaches, cognitive impairments, sleep disturbance, and dyslexia evident when fatigued) may be common in children and adolescents. Episodes of intense post-exertional malaise may occur, eventually causing a previously active child to reduce or avoid physical activity.”

(5) “Although the panel that developed the ICC considers its criteria appropriate for diagnosing only ME, we consider the ICC helpful in establishing an MDI of CFS because of the similarities between CFS and ME. For example, ME also is a systemic disorder that manifests many of the same symptoms as CFS, including prolonged fatigue. Medical experts who consider ME to be a subtype of CFS may use hybrid terms to describe the syndrome, such as CFS/ME and ME/CFS. We adapted the CDC criteria, CCC, and ICC because the Act and our regulations require a claimant to establish by objective medical evidence that he or she has a medically determinable impairment.”

(7) This last footnote indicates that medical findings and tests outlined in both the Canadian Criteria and the Consensus Criteria may be used in documenting a case of CFS. Again, this statement is a major step forward in CFS/ME recognition and advocacy, though undoubtedly full use of the two newer definitions will take time to be implemented. However, physicians and attorneys should make full use of the definitions when necessary and appropriate, in conjunction with the CDC definition.

Application of 2016 SSR 16-p Social Security Ruling “Evaluation of Symptoms in Disability Claims” to ME-CFS Disability Claims.

A separate Ruling: SSR 16-p was issued to instruct examiners and adjudicators on how a claimant’s symptoms should be evaluated in light of both objective medical evidence (medical

signs and lab tests), and the entire record, including non-medical evidence. As ME-CFS symptoms are important in both diagnosis and their effect on a person's ability to work, the Ruling would be applied to CFS disability evaluation.

The Ruling and its application to the CFS disability evaluation will be summarized here. We will post a detailed review of the entire symptom Ruling.

The Ruling states: “We define a symptom as the individual’s own description of his or her physical or mental impairments... In determining disability all of the patient’s individual symptoms, including pain, and the extent to which the symptoms can reasonably be accepted as consistent with the objective medical and other evidence in the individual’s record.”

The Ruling requires that a person’s symptoms and their severity, persistence and disabling effects on the ability to work should be reasonably consistent with objective medical evidence – however: there are times when the intensity or nature of the person’s symptoms may not be entirely reflected in the objective medical evidence in the record. For instance, the post-exertional malaise a person experiences may be greater than indicated by medical signs or lab tests.

When such an “inconsistency” occurs, examiners must seek to clarify medical evidence, but also must take into account evidence in the record from other sources which may help to verify or detract from the level of symptoms.

Other sources of evidence include medical sources, non-medical sources, and other factors: Important information about symptoms recorded by medical sources and reported in the medical evidence may include, but is not limited to, the following:

- “Onset, description of the character and location of the symptoms, precipitating and aggravating factors, frequency and duration, change over a period of time (e.g., whether worsening, improving, or static), and daily activities. Very often, the individual has provided this information to the medical source, and the information may be compared with the individual's other statements in the case record. In addition, the evidence provided by a medical source may contain medical opinions about the individual's symptoms and their effects. Our adjudicators will consider such opinions by applying the factors in 20 CFR 404.1520c and 416.920c.^[15]
- A longitudinal record of any treatment and its success or failure, including any side effects of medication.
- Other sources may provide information from which we may draw inferences and conclusions about an individual's statements that would be helpful to us in assessing the intensity, persistence, and limiting effects of symptoms. Examples of such sources include public and private agencies, other practitioners, educational personnel, non-medical sources such as family and friends, and agency personnel. We will consider any statements in the record noted by agency personnel who previously interviewed the individual, whether in person or by telephone. The adjudicator will consider any personal

observations of the individual in terms of how consistent those observations are with the individual's statements about his or her symptoms as well as with all of the evidence in the file.”

“d. Factors to Consider in Evaluating the Intensity, Persistence, and Limiting Effects of an Individual's Symptoms: In addition to using all of the evidence to evaluate the intensity, persistence, and limiting effects of an individual's symptoms, we will also use the factors set forth in 20 CFR 404.1529(c)(3) and 416.929(c)(3). These factors include:

1. Daily activities;
2. The location, duration, frequency, and intensity of pain or other symptoms;
3. Factors that precipitate and aggravate the symptoms;
4. The type, dosage, effectiveness, and side effects of any medication an individual takes or has taken to alleviate pain or other symptoms;
5. Treatment, other than medication, an individual receives or has received for relief of pain or other symptoms;
6. Any measures other than treatment an individual uses or has used to relieve pain or other symptoms (e.g., lying flat on his or her back, standing for 15 to 20 minutes every hour, or sleeping on a board); and
7. Any other factors concerning an individual's functional limitations and restrictions due to pain or other symptoms.”

The Symptom Ruling also states that Social Security examiners may evaluate a claimant’s behavior in attempting to treat their symptoms: “We will consider an individual's attempts to seek medical treatment for symptoms and to follow treatment once it is prescribed when evaluating whether symptom intensity and persistence affect the ability to perform work-related activities for an adult or the ability to function independently, appropriately, and effectively in an age- appropriate manner for a child with a title XVI disability claim. Persistent attempts to obtain relief of symptoms, such as increasing dosages and changing medications, trying a variety of treatments, referrals to specialists, or changing treatment sources may be an indication that an individual's symptoms are a source of distress and may show that they are intense and persistent.^[18]”

Lack of such “treatment behavior” may or may not affect Social Security’s evaluation of the presence and intensity of symptoms. For instance, failure to follow treatment programs or take medications may reflect negatively on a patient’s symptom report. On the other hand, the Ruling requires that possible reasons for such failure must be taken into account:

- An individual may have structured his or her activities to minimize symptoms to a tolerable level by avoiding physical activities or mental stressors that aggravate his or her symptoms.
- An individual may receive periodic treatment or evaluation for refills of medications because his or her symptoms have reached a plateau.
- An individual may not agree to take prescription medications because the side effects are less tolerable than the symptoms.
- An individual may not be able to afford treatment and may not have access to free or low-cost medical services.
- A medical source may have advised the individual that there is no further effective treatment to prescribe or recommend that would benefit the individual.
- An individual's symptoms may not be severe enough to prompt him or her to seek treatment, or the symptoms may be relieved with over the counter medications.
- An individual's religious beliefs may prohibit prescribed treatment.
- Due to various limitations (such as language or mental limitations), an individual may not understand the appropriate treatment for or the need for consistent treatment of his or her impairment.
- Due to a mental impairment (for example, individuals with mental impairments that affect judgment, reality testing, or orientation), an individual may not be aware that he or she has a disorder that requires treatment.

There are a number of important “take-aways” from the Symptom Ruling as it applies to CFS. First an applicant, after MDI CFS diagnosis, should gather as much objective medical evidence as possible to validate their symptoms and the severity, intensity and persistence of their symptoms. Besides any lab or other tests, medical signs might include: “The intensity, persistence, and limiting effects of many symptoms can be clinically observed and recorded in the medical evidence.” Examples would be low grade fevers, any breathing difficulties, rapid heartbeat, low grade fevers, difficulty in walking and abnormal tiredness, cognitive difficulties, and many other symptoms.

Second, the person should gather as much other evidence from medical and non-medical sources to corroborate their symptoms and the limitations caused by them.

All of this information should be communicated to one’s treating physicians who may be able to evaluate it for his or her disability medical report. All of the documentation should also be submitted to Social Security by the various non-medical sources. The claimant should also, as much as possible be consistent in their report of symptoms, even if they vary. If the claimant must appeal, his or her attorney should be aware of the symptom Ruling. CFS is an MDI that requires a greater evaluation of symptoms than many other illnesses.

APPENDIX II

OBTAINING A CFS DIAGNOSIS USING THE 1994 CDC CFS DEFINITION

Note: *This section detailing diagnosis under the 1994 CDC definition is long and detailed, and in many ME/CFS cases at some point may no longer apply to disability applications since portions of the Criteria are outdated and may be superseded by the 2014 Ruling and the newer Canadian and International Criteria, as well as the newer 2015 IOM-CDC Criteria. However as yet the Social Security Administration has not, as far as we know, accepted the new 2015 IOM-CDC Criteria. The SSA would have to issue a new Ruling to recognize the new Criteria. It is important to know how the illness is currently diagnosed for Social Security and may be relevant for LTD benefits*

As already discussed, the SSA Ruling still recognizes the 1994 CDC definition as the primary method of diagnosis. For disability purposes in 2021, a physician could state s/he has diagnosed the illness according to the 1994 CDC definition; the 2003 ME/CFS Canadian Definition; the ICC definition and even the 2015 CDC definition (as long as at least one of the first three are included.)

The 1994 Centers for Disease Control Diagnostic Criteria for Chronic Fatigue Syndrome, was published in an article, "The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study," published in the *Annals of Internal Medicine*, December, 1994.

The 2003 Canadian Criteria was published under the title: "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols," in the *Journal of Chronic Fatigue Syndrome*, Vol. 11, Number 1, 2003. This definition is far superior to any previously widely-disseminated 1994 CDC definition and will probably be used by some doctors to make clinical diagnoses.

We do include this section because some of the issues and exclusions raised by the 1994 CDC Criteria may arise with physicians (and even Social Security) who are only familiar with this older definition.

Note; This is a long and detailed section, so readers may wish to look through the rest of the booklet and then come back to further understand more of the diagnostic issues.

Obtaining a well-documented ME/CFS or Fibromyalgia diagnosis is a crucial first step in obtaining disability benefits. Unfortunately, many patients still have difficulty obtaining a diagnosis because their physicians do not know how to diagnose or lack confidence in making the diagnoses.

Physicians who are not well-informed about the illness may benefit from reviewing the 4

different diagnostic criteria for ME/CFS and CFS. The 4 Criteria can be found through the links on page 17 of this booklet. For Social Security applications it is prudent for the illness to be diagnosed first with the 1994 CDC Criteria and then to be supplemented with full documentation using the 2003 Canadian Criteria or the 2011 ICC Criteria. In 2020, Doctors will begin to be exposed to the 2015 definition.

Here we will review the diagnostic process under the 1994 Case definition and Diagnostic Criteria.

Under these guidelines, the diagnostic process for CFS is divided into three primary phases:

1. The *Clinical Evaluation Phase*, which consists of a medical and psychological history and evaluation; and laboratory screening tests.
2. The *Exclusion/Inclusion Phase* is divided into two parts: an *Exclusion Phase* and an *Inclusion Phase*. Based on the finding of certain illnesses and conditions other than CFS during the Clinical Evaluation Phase, an additional diagnosis of CFS may at this point be excluded. Or, alternatively, a subsequent diagnosis of CFS may still be permitted (despite the finding of a different illness or condition).
3. The *CFS Diagnosis Phase* is the actual diagnosis of CFS based on a specific symptom profile. The guidelines also contain the new diagnosis of idiopathic chronic fatigue, which is chronic fatigue which fails to meet the criteria for the Chronic Fatigue Syndrome and remains unexplained despite the comprehensive clinical evaluation prescribed by the guidelines.

This next section consists of a detailed summary and explanation of the procedure for obtaining and documenting a CFS diagnosis based on the CDC guidelines.

Clinical Evaluation Phase: An individual suffering from chronic fatigue (defined as: self-reported persistent or relapsing fatigue, lasting six or more consecutive months) is required to undergo the following clinical evaluation. This is to identify underlying or contributing conditions that require treatment and that may either exclude or permit a further diagnosis of CFS. The steps in clinical evaluation are as follows:

1. A thorough history that covers medical and psycho-social circumstances at the onset of fatigue, depression or other psychiatric disorders; episodes of medically unexplained symptoms; alcohol or other substance abuse; and current use of prescription and over-the-counter medications and food supplements.
2. A mental status examination to identify abnormalities in mood, intellectual function, memory, and personality. Particular attention should be directed toward current symptoms of depression or anxiety, self-destructive thoughts, and observable signs such as psychomotor retardation. Evidence of a psychiatric or neurologic disorder requires that an appropriate psychiatric, psychological, or neurologic evaluation be done.

In these two initial steps of evaluation, in addition to a medical evaluation, there is a clear emphasis on evaluating possible psychiatric conditions. This emphasis on psychiatric evaluation may create problems for some individuals with ME/CFS in obtaining a diagnosis and in applying for Social Security. By understanding the potential pitfalls of psychiatric evaluation, an informed individual with ME/CFS can avoid and minimize the effect of unnecessary and misguided psychiatric evaluation in his/her effort to obtain a diagnosis and social security benefits. The introduction of a finding of depression into the CFS diagnostic process and in an application for Social Security can complicate or may even jeopardize obtaining a diagnosis and gaining disability benefits. (The distinction here between the current name ME/CFS and the Social Security name of CFS may be noticed.)

Item 1 (just quoted) requests an evaluation of any depression, both preceding and following the onset of the fatiguing illness. It is critical for the diagnosis of CFS and for the Social Security application that the patient and the physician clearly distinguish between a primary and secondary depression. A primary depression, either currently or in the past, could exclude or make more difficult a diagnosis of CFS; while a finding of secondary depression can be very consistent with a CFS diagnosis. Secondary depression often occurs as a reaction to a chronic physical illness as an individual's response to a lack of physical improvement and the limitations imposed by the illness. Also any evaluation of a history of depression prior to the illness' onset should distinguish between major severe chronic depression, and infrequent episodes of minor depression. For a full explanation of the importance of evaluating depression for both diagnostic purposes and in applying for Social Security, see other pages in this booklet, including Appendix VI.

Item 2 (quoted above) in this evaluation phase requires "a mental status examination" for all patients to be given by the diagnosing physician. The term, "mental status examination", does not refer to any standardized or formal test or procedure of evaluation; instead, the term refers to a fairly informal and basic assessment of the presence of any disorders or symptoms listed in item 2; certainly what constitutes a "mental status examination" will vary among examining physicians. Item 2 indicates that if evidence of a psychiatric or neurological disorder is found, then a further psychiatric, psychological or neurological evaluation would be required.

Here there is a potential pitfall for a genuine ME/CFS sufferer. Many ME/CFS patients do not suffer from significant depression or other emotional disorder because of their illness; however, they do suffer the expected emotional trouble and frustrations that result from a chronic physical illness. Since these individuals do not suffer from a "psychiatric disorder," they should discuss with their physician any requested psychiatric evaluation. Such evaluations occasionally result in a psychiatric misdiagnosis which then can complicate the diagnostic process as well as the individual's Social Security application. Even an individual who suffers from significant secondary depression due to the ME/CFS should discuss with his or her examining physician whether the level of depression warrants a further psychiatric referral.

If such a referral is made the patient should explain to the specialist that the depression is a result of their physical illness. Also during this mental status examination it is important for the patient and the physicians to distinguish cognitive dysfunction (memory and thinking problems) and neurological problems caused by the CFS from psychologically caused conditions. For more information on cognitive dysfunction caused by CFS, as opposed to psychological disorder, see other sections of this booklet. Referrals to specialists who understand ME/CFS for the assessment of cognitive dysfunction and neurological disorder can certainly be helpful in a diagnostic process and in the Social Security application process.

The next items in the evaluation phase provide for:

“3. A thorough physical examination.

4. A minimum battery of laboratory screening tests including complete blood count with leukocyte differential; erythrocyte sedimentation rate; serum levels of alanine aminotransferase, total protein, albumin, globulin, alkaline phosphatase, calcium, phosphorus, glucose, blood urea nitrogen, electrolytes, and creatinine; determination of thyroid-stimulating hormone; and urinalysis...

...further tests may be indicated on an individual basis to confirm or exclude another diagnosis, such as multiple sclerosis. In these cases, additional tests or procedures should be done according to accepted clinical standards.”

The continuing text of this section of the CDC criteria discourages use of further tests such as MRIs or other imaging, immune, neurological, sleep studies, endocrine testing.

This portion regarding excluded tests is superseded by the 2014 Ruling and should be disregarded.

The second phase of the diagnostic process may be called the *Exclusion/inclusion Phase*.

Findings of the *Evaluation Phase* may either exclude a diagnosis of CFS or allow for a diagnosis of CFS. The first part of this phase is the *Exclusion Phase*. Under these guidelines the finding of an exclusionary illness or condition prevents a diagnosis of CFS. However, the finding of an exclusionary condition does not necessarily mean that an individual does not have CFS. The guidelines make clear that they were designed for research purposes in order to maintain research clarity; a diagnosis of CFS has been excluded when other illnesses or conditions are present. The guidelines themselves state:

“...none of the components, including the revised case definition of the Chronic

Fatigue Syndrome, can be considered definitive.”

Despite an excluding condition, a person with CFS may still obtain a diagnosis from a doctor who is well-informed about CFS. Such an individual can and should apply for Social Security benefits if he or she is disabled.

The guidelines proceed as follows:

“The following conditions exclude a patient from the diagnosis of unexplained chronic fatigue (which includes Chronic Fatigue Syndrome):

1. Any active medical condition that may explain the presence of chronic fatigue (31), such as untreated hypothyroidism, sleep apnea, and narcolepsy, and iatrogenic conditions such as side effects of medication...
2. ...Any previously diagnosed medical condition whose resolution has not been documented beyond reasonable clinical doubt and whose continued activity may explain the chronic fatiguing illness. Such conditions may include previously treated malignancies and unresolved cases of hepatitis B or C virus infection.”

Note: Despite the guidelines, it is possible that an individual with another previously diagnosed illness which causes fatigue could also have Chronic Fatigue Syndrome.

“3. Any past or current diagnosis of a major depressive disorder with psychotic or melancholic features; bipolar affective disorders; schizophrenia of any subtype; delusional disorders of any subtype; dementia of any subtype; anorexia nervosa; or bulimia nervosa.”

Here the guidelines state that any current or previous major mental illness or bulimia or anorexia nervosa disqualifies an individual from receiving a diagnosis of CFS. Again, despite the guidelines, an individual with one of these conditions, either in the past or the present, could suffer from CFS, receive a diagnosis for CFS, and receive Social Security on the basis of a CFS disability. For instance, an individual could develop CFS even though he or she had recovered from a major depression ten years previously. Again, individuals who have recovered from anorexia nervosa or bulimia nervosa could develop CFS years later. The guidelines clearly recognize these possibilities:

“We distinguish between psychiatric conditions for pragmatic reasons. It is difficult to interpret symptoms typical of the Chronic Fatigue Syndrome in the setting of illnesses such as major psychotic depression or schizophrenia. More importantly, care of these persons should focus on their chronic psychiatric disorder.”

Again individuals with these exclusionary conditions who also have Chronic Fatigue Syndrome should seek diagnosis from a doctor experienced in the diagnosis of Chronic Fatigue Syndrome and may apply for disability benefits on the basis of Chronic Fatigue Syndrome once a diagnosis has been made. Also it should be noted (see below) that other psychiatric

conditions do not exclude a diagnosis of CFS under these guidelines.

“4. Alcohol or other substance abuse within 2 years before the onset of the chronic fatigue and at any time afterward.”

Again it is quite possible for a person who two years previously suffered from substance abuse to develop CFS and to be diagnosed accordingly.

“5. Severe obesity (32, 33) as defined by a body mass index [body mass index = weight in kilograms / (height in meters)²] equal to or greater than 45.

Any unexplained physical examination finding or laboratory or imaging test abnormality that strongly suggests the presence of an exclusionary condition must be resolved before further classification.”

Note: Again despite the guidelines the possibility exists, as discussed above, that an individual with severe obesity could also suffer from CFS.

The second part of this phase is the ***Inclusion Phase***. That is, the finding of conditions that do not exclude an additional diagnosis of CFS.

“1. Any condition defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, including fibromyalgia, anxiety disorders, somatoform disorders, nonpsychotic or non-melancholic depression, neurasthenia, and multiple chemical sensitivity disorder.”

This step obviously allows for diagnoses of Fibromyalgia/CFS and multiple chemical sensitivity disorder/CFS. This step also allows for a CFS diagnosis even in the presence of the listed psychiatric conditions including non-psychotic depressions and anxiety disorders. This portion of the guidelines is a major improvement over the 1988 CDC guidelines since it clearly states both to physicians and Social Security that an entire group of psychiatric conditions do not and must not necessarily exclude a diagnosis of CFS. Under these new guidelines neither a psychiatrist nor Social Security can summarily dismiss a diagnosis of CFS to an individual with one of these psychiatric disorders. The finding of the following illnesses or conditions do not exclude a diagnosis of CFS:

“ 2. Any condition under specific treatment sufficient to alleviate all symptoms related to that condition and for which the adequacy of treatment has been documented. Such conditions include hypothyroidism for which the adequacy of replacement hormone has been verified by normal thyroid-stimulating hormone levels, or asthma in which the adequacy of treatment has been determined by pulmonary function and other testing.

3. Any condition, such as Lyme disease or syphilis that was treated with definitive therapy before development of chronic symptomatic sequelae.

4. Any isolated and unexplained physical examination finding or laboratory or

imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition. Such conditions include an elevated antinuclear antibody titer that is inadequate to strongly support a diagnosis of a discrete connective tissue disorder without other laboratory or clinical evidence.”

The final CFS diagnostic phase of the CFS diagnostic process provides guidelines for the actual diagnosis of Chronic Fatigue Syndrome. An individual's chronic fatigue will be diagnosed according to the following CFS guidelines unless his or her chronic fatigue has been already "explained" through an exclusionary condition. The guidelines for CFS diagnosis are as follows:

“A case of the chronic fatigue syndrome is defined by the presence of the following:

- 1) clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities; and
- 2) the concurrent occurrence of four or more of the following symptoms, all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue: self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities; sore throat; tender cervical or axially lymph nodes; muscle pain, multi-joint pain without joint swelling or redness; headaches of a new type, pattern, or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours.”

These guidelines complete the diagnosis of Chronic Fatigue Syndrome. If, however, chronic fatigue is not explained through a diagnosis of CFS or a previously explained (excluded) condition, a final diagnosis of idiopathic chronic fatigue may be reached.

“A case of Idiopathic Chronic Fatigue is defined as clinically evaluated, unexplained chronic fatigue that fails to meet criteria for the Chronic Fatigue Syndrome. The reasons for failing to meet the criteria should be specified.”

For instance (interpreting under these guidelines), an individual who had fully recovered from a major psychotic depression twenty years previously and who now develops disabling chronic fatigue and who under these guidelines is not eligible for a CFS diagnosis might well receive a diagnosis of idiopathic chronic fatigue.

The question arises whether an individual who is applying for Social Security and who actually has CFS, but is excluded under the new Criteria should apply under the diagnosis of idiopathic chronic fatigue or instead, despite the guidelines, should attempt to obtain a CFS diagnosis from a qualified physician.

The answer is, if at all possible, for the disability application to be made under a CFS diagnosis since CFS is a formally recognized diagnosis under Social Security regulations. Idiopathic chronic fatigue is not such a formally recognized or listed diagnosis. Generally, a disabling CFS diagnosis would be more easily approved by Social Security than a disabling diagnosis of idiopathic chronic fatigue.

Special note: In 2021 the new Ruling and newer definitions pretty much have superseded the Ideopathic Chronic Fatigue diagnosis. Such a diagnosis would only very rarely be used, and given its uncertainty might not yield a positive outcome. In any case, any medical diagnosis must demonstrate severe disability. The idiopathic chronic fatigue diagnosis, for all practical purposes, except in rare instances, may be generally ignored.

In such circumstances the diagnostic method would be to evaluate according to the criteria, but not to eliminate CFS on the basis of the pertinent exclusion. The CFS would then be diagnosed on the basis of the symptom profile. Especially important in this type of diagnosis would be the documentation of history, treatments and the extent of resolution of any previous or current illness or condition that qualifies as exclusionary. Documentation of lab and other testing showing consistency with CFS and inconsistency with the exclusionary illness would be especially important. For example, in the case of a patient with CFS who recovered twenty years previously from a major psychotic depression, the physician would perform all the steps according to the criteria except for eliminating CFS on the basis of the former depression. The physician would then document the history, treatment and resolution of the former depression. Symptoms and lab and other testing results showing abnormalities consistent with CFS and inconsistent with psychotic depression would be emphasized.

Patients with CFS, who also have new exclusionary conditions, should find the list of symptoms and list of tests helpful in working with their physicians to document their CFS: "Some tests to be conducted to help determine objectivity of CFS/CFIDS and/or other disabling symptoms" and "Checklist of CFIDS symptoms" (for these lists see Appendix IV.)

Appendix III – Documenting Fibromyalgia to Social Security

Fibromyalgia may strike individuals as a separate illness. Or individuals may have FM combined with ME/CFS. The following is a medical definition of FM:

“What is Fibromyalgia” (from the Mass. ME/CFS&FM Association brochure), and **the 1990 American College of Rheumatologists diagnostic criteria.**

“Fibromyalgia means ‘soft tissue and muscle pain’. The soft tissues are tendons or ligaments. FM is a chronic pain syndrome often associated with ME/CFS, and sometimes confused with it. The pain can be severe enough to interfere with routine daily activities. The pain migrates, can be achy, throbbing, shooting, or stabbing, and is worse in areas used most, like the neck or back. FM is associated with “tender points” which are painful when pressure is applied to them. Individuals often say they awaken feeling as if they hadn’t slept. A sudden onset of profound fatigue can occur during or following exertion. Many other symptoms common to fibromyalgia, including stiffness on waking, memory, and concentration problems, excessive sensitivity of the senses, headaches, Temporomandibular Joint Syndrome (TMJ), irritable bowel, and bladder and muscle spasm.”

For a percentage of FM patients the illness is disabling to the extent people are unable to work. The illness is recognized by Social Security. In 2012 the Social Security Administration issued a Ruling setting forth the standards for finding an FM patient disabled.

Social Security SSR 12-2p: Evaluation of Fibromyalgia

The following is a discussion of the Social Security Ruling for the evaluation of Fibromyalgia disability claims:

In 2012 the Social Security Administration issued a **Policy Interpretation Ruling SSR 12-2p: Titles II and XVI: Evaluation of Fibromyalgia**

This Guidance, currently operable in 2021, 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.

This review of the Ruling will provide a basic understanding of the Ruling, but we urge those applying for an FM disability or those assisting them, including physicians or other providers, as well as advocates and attorneys, to read the full Ruling which includes diagrams of tender points. See the Ruling at: https://www.ssa.gov/OP_Home/rulings/di/01/SSR2012-02-di-01.html

Disclaimer: *This review and evaluation of the Ruling contains the opinions of the author as to how claimants, physicians, attorneys and others might utilize the policies and language in the Ruling in the effort to document FM disability claims.*

While these opinions are based on the language of the Ruling, as well as extensive experience with the Social Security disability process, there is no way to accurately know in what manner the Social Security Administration and associated agencies will, in practice, implement the new Ruling. The Ruling will likely not be applied or interpreted uniformly at all administrative levels or geographic areas of evaluation. Some elements of the Ruling are likely to be given more emphasis than others; nor is the Ruling expected to remain static in its application over time.

In regard to the documentation of medical signs, symptoms, medical tests and functional evaluation, it is only possible, at this time, to make reasonable inferences from the Ruling's language as to how FM claims might be evaluated; however, these inferences cannot be expected to predict how the different signs, symptoms and tests will actually be evaluated.

Therefore, Kenneth Casanova, other authors/contributors of this booklet, and the Massachusetts ME/CFS & FM Association assume no responsibility for any use of this document by its readers for any results or consequences of such usage or further, for any other activity which occurs from the reading of the document or the application of its content. This document is not intended to be a substitute of the advice of a competent attorney who is well-versed on the Ruling and the disability evaluation process. For legal advice it is imperative to consult with such an attorney or qualified legal advocate of the reader's own choosing.

The Introduction to the Ruling begins: "FM is a complex medical condition characterized by widespread pain in the joints, muscles, tendons or nearby soft tissues that has persisted for at least 3 months...When a person seeks disability benefits due in whole or in part to FM, we must properly consider a person's symptoms when we decide whether the person has an MDI of FM."

[Note: In order to obtain disability benefits an individual must first be diagnosed by a physician to have a medically determinable impairment (MDI) – that is an accepted medical illness or condition that is diagnosed according to medically defined criteria. Fibromyalgia is a medically determinable impairment.]

However, the Ruling further states: "As with any claim for disability benefits, before we find that a person with an MDI is disabled, we must ensure there is sufficient objective evidence to support a finding that the person's impairment(s) so limits the person's functional abilities that it precludes him or her from performing substantial gainful activity."

Here Social Security makes a critical distinction between a person's self-report of symptoms – sometimes called "subjective" evidence -- and objective evidence, that is, detailed evidence from medical and other sources. Because FM is largely an illness defined by symptoms and a person's self-report of the severity of symptoms, it is critical also to fully document such objective

evidence – these different types of objective evidence will be fully discussed below.

The Introduction also states that not only must the person be diagnosed with FM, but that it must be so disabling as to prevent the person from engaging in “substantial gainful activity.” The Ruling also states: “If the person with FM is doing substantial gainful activity, we [will] find that he or she is not disabled.”

Comment: “Substantial gainful activity” in relation to FM may be ill-defined. Based on our experience with scores of ME/CFS claims, and advice from a number of experienced attorneys, any patient working for an even limited number of hours at the time of application risks a finding of performing substantial gainful activity. We have no reason to believe that substantial gainful activity is defined differently in the case of FM. Limited part-time hours, say 8-10 hours a week may or may not be considered substantial gainful activity depending on the type of work and, to an extent, the claimant’s past work experience. Therefore, while applying, it is generally best not to be employed at all, based on our experience. If a person must work, it should be generally less than 8 hours per week, and at a job that requires very little effort. Still, to do so, may jeopardize a disability application. After an application is approved, there is some greater allowance for work.

The first step in making an FM claim is that the applicant must provide documentation from a physician that he or she has been properly diagnosed with the illness.

In establishing a diagnosis of FM, the Ruling reads: “Generally, a person can establish that he or she has an MDI of FM by providing evidence from an acceptable medical source. A licensed physician (a medical or osteopathic doctor) is the only medical source who can provide such evidence.”

First the physician must provide evidence that he or she has diagnosed the illness according to at least one of the two medically-accepted diagnostic criteria:

- 1) the 1990 American College of Rheumatology (ACR) Criteria for the Classification of Fibromyalgia; or
- 2) the 2010 ACR Preliminary Diagnostic Criteria

Importantly, the Ruling states a preference of the use of the 1990 Criteria: “...two sets of criteria for diagnosing FM, which we generally base on the 1990...(ACR) Criteria.”

Hence, the individual applying for disability should inform their physician to document the FM diagnosis according to, at the least, the 1990 Criteria. (This Criteria provides more substantial objective evidence: trigger points.)

How is a diagnosis made according to the 2 criteria?

A. “The 1990 ACR Criteria for the Classification of Fibromyalgia. Based on these criteria, we may find that a person has an MDI of FM if he or she has all three of the following:

1. A history of widespread pain—that is, pain in all quadrants of the body (the right and left sides of the body, both above and below the waist) and axial skeletal pain (the cervical spine, anterior chest, thoracic spine, or low back)—that has persisted (or that persisted) for at least 3 months. The pain may fluctuate in intensity and may not always be present.

2. At least 11 positive tender points on physical examination (see diagram below). The positive tender points must be found bilaterally (on the left and right sides of the body) and both above and below the waist.

a. The 18 tender point sites are located on each side of the body at the:

- Occiput (base of the skull);
- Low cervical spine (back and side of the neck); Trapezius muscle (shoulder);
- Supraspinatus muscle (near the shoulder blade); Second rib (top of the rib cage near the sternum or breast bone);
- Lateral epicondyle (outer aspect of the elbow);
- Gluteal (top of the buttock);
- Greater trochanter (below the hip); and
- Inner aspect of the knee.

b. In testing the tender-point sites,^[6] the physician should perform digital palpation with an approximate force of 9 pounds (approximately the amount of pressure needed to blanch the thumbnail of the examiner). The physician considers a tender point to be positive if the person experiences any pain when applying this amount of pressure to the site.

3. Evidence that other disorders that could cause the symptoms or signs were excluded. Other physical and mental disorders may have symptoms or signs that are the same or similar to those resulting from FM.^[7] Therefore, it is common in cases involving FM to find evidence of examinations and testing that rule out other disorders that could account for the person's symptoms and signs. Laboratory testing may include imaging and other laboratory tests (for example, complete blood counts, erythrocyte sedimentation rate, anti-nuclear antibody, thyroid function, and rheumatoid factor).”

By obtaining the Criteria at the Social Security website (see above) one can see diagrams of the tender points on the human body.

Note: Section 3 in the Criteria should not be ignored. *The doctor must provide medical documentation/evidence that other illnesses/conditions with signs and symptoms and symptoms*

similar or the same as FM have been ruled out. This constitutes objective evidence.

“B. *The 2010 ACR Preliminary Diagnostic Criteria.* Based on these criteria, we may find that a person has an MDI of FM if he or she has all three of the following criteria^[8]:

1. A history of widespread pain (see section II.A.1.); [This refers to point 1 in the 1990 Criteria.]
2. Repeated manifestations of six or more FM symptoms, signs,^[9] or co-occurring conditions,^[10] especially manifestations of fatigue, cognitive or memory problems (“fibro fog”), waking unrefreshed,^[11] depression, anxiety disorder, or irritable bowel syndrome; and
3. Evidence that other disorders that could cause these repeated manifestations of symptoms, signs, or co-occurring conditions were excluded (see section II.A.3.).”

In number two: cognitive or memory problems might be objectively confirmed through neuropsychological testing. However, if performed by a tester who is ignorant of how to interpret the test with respect to FM, then the test results might indicate a psychological disorder rather than FM. Such a finding could jeopardize an FM claim. Hence, if one cannot find a tester with FM expertise, it would be better not to undertake such a test.

A sleep study could also confirm “unrefreshed sleep” – a sleep disorder. Again, finding a tester familiar with FM as a physiological illness who is competent to evaluate results consistent with FM is a must before undertaking the test.

Very important: It is not enough for the physician to simply state his or her diagnosis of FM. Documentation of how the physician reached the diagnosis must be provided: “The evidence must document that the physician reviewed the person’s medical history and conducted a physical exam. We will review the physician’s treatment notes to see if they are consistent with FM, determine whether the person’s symptoms have improved, worsened or remained stable over time, and establish the physician’s assessment of the person’s physical strength and functional abilities.” (This medical documentation is considered objective.)

Documenting the Diagnosed Fibromyalgia as severe and disabling:

It is not enough simply to document that the applicant has been diagnosed with an MDI of FM, the illness must also be found to be severe and disabling: “...we must ensure there is sufficient objective evidence to support a finding that the person’s impairment(s) so limits the person’s functional abilities that it precludes him or her from performing any substantial gainful activity.” The Ruling goes on to discuss the types of documentation required for the number of steps in determining not only whether the person has FM, but also whether the FM disables him or her from working.

“When a person alleges FM, longitudinal records reflecting ongoing medical treatment from

acceptable medical sources are especially helpful in establishing both existence and severity of the impairment... We will generally request evidence for the 12-month period before the date of application unless we have reason to believe that we need evidence from an earlier period, or unless the alleged onset of disability is less than 12 months before the date of application. In the latter case we may still request evidence from before the alleged onset date if we have reason to believe that it could be relevant to a finding about the existence, severity, or duration of the disorder, or to establish the onset of disability.”

Note: The date of disability is defined as the date a person becomes so disabled that he or she is unable to do any work on a predictable basis. A person with diagnosed FM becomes eligible for payments from the date of disability. Therefore, if they apply for disability after their date of disability – even if it occurred substantially before application, and if the chronology of the disability can be documented, then the person can claim any retroactive benefits.

“B. Other sources of evidence: 1. In addition to obtaining evidence from a physician, we may request evidence from other acceptable medical sources, such as psychologists, both to determine whether the person has another MDI(s) and to evaluate the severity and functional effects of FM or any of the person’s other impairments. We may also consider evidence from medical sources who are not ‘acceptable medical sources’ to evaluate the severity and functional effects of the impairment(s)”...

Issue of psychological misdiagnosis: If a person with FM is depressed or anxious, it is important for any psychologist, psychiatrist, or social worker to clearly note, if true, that the mental symptoms are a result of the chronic physical illness – and not an alternative diagnosis to the FM. The emotional symptoms are “secondary” to FM and would not be occurring if the FM was not present. Otherwise, Social Security could negate the MDI of FM and deny the claim. It is possible one could have FM and another separate emotional/mental illness – in this case the FM must be clearly and independently verified. If a person with FM is referred for a psychological evaluation, then the referral should be made to a professional familiar with FM. If depression and/or anxiety is secondary to FM, then there could be multiple MDIs which could add to the disability.

****Important Caution: If a patient is also on, or applying for, long-term disability insurance, he or she should carefully examine their disability policy. Different policies use different language relating to the effect of depression, anxiety, or other mental impairments on long-term disability eligibility.*

Some policies may state that if a mental impairment simply “contributes to” the physically-based FM disability, then the patient will be ineligible for long-term disability insurance or the benefits will be limited to a relatively short time period.

If this language is in the disability policy, then the physician documenting FM for Social Security should clearly note that the depression, anxiety, etc. does not, in any way, contribute to the

disability – that the disability and the inability to work is entirely the result of the C.F.S.

For the patient who is applying for, or already receiving, both LTD and Social Security benefits, it is critical to utilize a single knowledgeable attorney who is familiar with FM, as well as being competent in representation for both Social Security and LTD benefits. As just discussed, how the person is represented for Social Security can have profound effects on their LTD eligibility. Having one attorney make sure the representation for both is coordinated is essential. The patient should not accept an insurance company's offer to provide an attorney to represent them before Social Security. Such representation can provide the insurance company with information that could affect eligibility for LTD benefits. If the insurance company offers to pay for an attorney of the claimant's choice, and such an attorney will not turn over the claimant's records to the insurance company, then the claimant might consider the company's offer.

One major symptom of many patients with FM is neurocognitive difficulty: including short-term memory loss, word-finding, information processing, visual-spatial difficulties, comprehension, concentration, speech, calculation, and other symptoms suggesting persistent neurocognitive impairment. Neurocognitive problems in FM could be identified by neuropsychological testing performed by a competent neuropsychologist familiar with FM. Presumably such testing could be objective medical evidence to confirm these symptoms. However, there are difficulties finding a qualified examiner: Neuropsychological testing will only be diagnostically helpful in the hands of an experienced tester familiar with FM. In the wrong and inexperienced hands such testing may falsely indicate a psychological disorder. Neuropsychological testing from an experienced FM tester is probably not easily available in many parts of the U.S. Such testing is also relatively expensive. Yet obtaining the proper neuropsychological testing may be one of the best ways, under these guidelines, to provide a positive laboratory finding.

2. "Under our regulations and SSR 06-3p information from nonmedical sources may also help us evaluate the severity and functional aspects of FM. This information may help us to assess the person's ability to function day-to-day and over time. It may also help us when we make findings about the credibility of the person's allegations about symptoms and their effects."

"Examples of non-medical sources include: neighbors, relatives, friends, clergy; past employers, rehabilitation counselors, and teachers; and Statements from SSA personnel who interviewed the person."

If the SSA determines there is insufficient evidence to determine an MDI of FM, or if the MDI is disabling, examiners may contact the person's treating physician or other sources, request additional records, or make a decision based on existing evidence. Additionally, SSA may arrange for a Consulting Examiner to determine if the person has FM or is disabled, or to assess the functional effects of the FM MDI or any other impairments, or also to determine if the duration requirement is met.

If a Consulting Examiner is utilized, "...it is important...[that] the CE has access to longitudinal clinical information about the person...However, we may rely on the CE even if the person who conducts the CE did not have access to the longitudinal evidence if we determine the CE is the most probative evidence in the case record."

Here it is important to note that if a person has been considering filing for disability to make sure they build a record that provides a physician's longitudinal office notes that document the diagnosis of FM and the illnesses disabling effects on their activities of daily living and ability to carry out work and employment tasks.

We will next discuss the steps in which Social Security assesses the applicants credibility as to their statements about their symptoms, their intensity and persistence – including their pain.

Evaluation of a person's statements about his or her symptoms and functional limitations:

This 2012 FM Ruling cites another SSA Ruling SSR-96-7p which establishes "Guidelines for the Evaluation of Symptoms in a Disability Claim" – particularly if objective medical evidence is sparse – and for the testing the credibility of an applicant's statements about their symptoms.

This symptom Ruling was itself superseded in 2016 by SSR 16-3p entitled "Evaluation of Symptoms in Disability Claims". The new Symptom Ruling is now most likely applied to the current 2012 FM Ruling being reviewed here. The 2016 "Evaluation of Symptoms in Disability Claims" is extensive and detailed and will certainly add to and elaborate the disability evaluation for FM.

The Ruling and its application to the FM disability evaluation will be summarized here. We will post a detailed review of the entire symptom Ruling.

The Ruling states: "We define a symptom as the individual's own description of his or her physical or mental impairments... In determining disability all of the patient's individual symptoms, including pain, and the extent to which the symptoms can reasonably be accepted as consistent with the objective medical and other evidence in the individual's record."

"Objective medical evidence", as distinguished from symptoms, is defined as medical signs and laboratory tests.

"*Signs* are anatomical, physiological, or psychological abnormalities established by medically acceptable clinical diagnostic techniques that can be observed apart from an individual's symptoms."^[4]

"*Laboratory findings* are anatomical, physiological, or psychological phenomena, which can be shown by the use of medically acceptable laboratory diagnostic techniques."

The Ruling requires that a person's symptoms and their severity, persistence, and disabling effects on the ability to work should be reasonably consistent with objective medical evidence –

however: there are times when the intensity or nature of the person's symptoms may not be entirely reflected in the objective medical evidence in the record. For instance, the pain a person experiences may be greater than indicated by medical signs or lab tests.

When such an inconsistency occurs, examiners must seek to clarify medical evidence, but also must take into account evidence in the record from other sources which may help to verify or detract from the level of symptoms.

Other sources of evidence include medical sources, non-medical sources, and other factors: Important information about symptoms recorded by medical sources and reported in the medical evidence may include, but is not limited to, the following:

- “Onset, description of the character and location of the symptoms, precipitating and aggravating factors, frequency and duration, change over a period of time (e.g., whether worsening, improving, or static), and daily activities. Very often, the individual has provided this information to the medical source, and the information may be compared with the individual's other statements in the case record. In addition, the evidence provided by a medical source may contain medical opinions about the individual's symptoms and their effects. Our adjudicators will consider such opinions by applying the factors in 20 CFR 404.1520c and 416.920c.^[15]
- A longitudinal record of any treatment and its success or failure, including any side effects of medication.
- Other sources may provide information from which we may draw inferences and conclusions about an individual's statements that would be helpful to us in assessing the intensity, persistence, and limiting effects of symptoms. Examples of such sources include public and private agencies, other practitioners, educational personnel, non-medical sources such as family and friends, and agency personnel. We will consider any statements in the record noted by agency personnel who previously interviewed the individual, whether in person or by telephone. The adjudicator will consider any personal observations of the individual in terms of how consistent those observations are with the individual's statements about his or her symptoms as well as with all of the evidence in the file.”

“d. Factors to Consider in Evaluating the Intensity, Persistence, and Limiting Effects of an Individual's Symptoms: In addition to using all of the evidence to evaluate the intensity, persistence, and limiting effects of an individual's symptoms, we will also use the factors set forth in 20 CFR 404.1529(c)(3) and 416.929(c)(3). These factors include:

8. Daily activities;
9. The location, duration, frequency, and intensity of pain or other symptoms;
10. Factors that precipitate and aggravate the symptoms;
11. The type, dosage, effectiveness, and side effects of any medication an individual takes or has taken to alleviate pain or other symptoms;

12. Treatment, other than medication, an individual receives or has received for relief of pain or other symptoms;
13. Any measures other than treatment an individual uses or has used to relieve pain or other symptoms (e.g., lying flat on his or her back, standing for 15 to 20 minutes every hour, or sleeping on a board); and
14. Any other factors concerning an individual's functional limitations and restrictions due to pain or other symptoms.”

The Symptom Ruling also states that Social Security examiners may evaluate a claimant’s behavior in attempting to treat their symptoms: “We will consider an individual's attempts to seek medical treatment for symptoms and to follow treatment once it is prescribed when evaluating whether symptom intensity and persistence affect the ability to perform work-related activities for an adult or the ability to function independently, appropriately, and effectively in an age- appropriate manner for a child with a title XVI disability claim. Persistent attempts to obtain relief of symptoms, such as increasing dosages and changing medications, trying a variety of treatments, referrals to specialists, or changing treatment sources may be an indication that an individual's symptoms are a source of distress and may show that they are intense and persistent.^[18]”

Lack of such “treatment behavior” may or may not affect Social Security’s evaluation of the presence and intensity of symptoms. For instance, failure to follow treatment programs or take medications may reflect negatively on a patient’s symptom report. On the other hand, the Ruling requires that possible reasons for such failure must be taken into account:

- “An individual may have structured his or her activities to minimize symptoms to a tolerable level by avoiding physical activities or mental stressors that aggravate his or her symptoms.
- An individual may receive periodic treatment or evaluation for refills of medications because his or her symptoms have reached a plateau.
- An individual may not agree to take prescription medications because the side effects are less tolerable than the symptoms.
- An individual may not be able to afford treatment and may not have access to free or low-cost medical services.
- A medical source may have advised the individual that there is no further effective treatment to prescribe or recommend that would benefit the individual.
- An individual's symptoms may not be severe enough to prompt him or her to seek treatment, or the symptoms may be relieved with over the counter medications.
- An individual's religious beliefs may prohibit prescribed treatment.

- Due to various limitations (such as language or mental limitations), an individual may not understand the appropriate treatment for or the need for consistent treatment of his or her impairment.
- Due to a mental impairment (for example, individuals with mental impairments that affect judgment, reality testing, or orientation), an individual may not be aware that he or she has a disorder that requires treatment.”

There are a number of important “take-aways” from the Symptom Ruling as it applies to FM. First an applicant, after MDI FM diagnosis, should gather as much objective medical evidence as possible to validate their symptoms and the severity, intensity and persistence of their symptoms. Besides any lab or other tests – including trigger points – medical signs might include: “The intensity, persistence, and limiting effects of many symptoms can be clinically observed and recorded in the medical evidence. Examples such as reduced joint motion, muscle spasm, sensory deficit, and motor disruption illustrate findings that may result from, or be associated with, the symptom of pain.^[10]”

Second, the person should gather as much other evidence from medical and non-medical sources to corroborate their symptoms and the limitations caused by them.

All of this information should be communicated to one’s treating physicians who may be able to evaluate it for his or her disability medical report. All of the documentation should be submitted to Social Security by the various non-medical sources. The claimant should also, as much as possible, be consistent in their report of symptoms, even if they vary. If the claimant must appeal, his or her attorney should be aware of the symptom Ruling. FM is an MDI that requires a greater evaluation of symptoms than many other illnesses.

The five step sequential evaluation process in determining if the FM patient is disabled:

Once the claimant has been found to have an MDI of FM, there is triggered the 5 step process. If the person is performing substantial gainful activity he or she is found not to be disabled (see above.)

Step 2 requires a finding that the person’s FM is “severe”.

“If we find that the person’s pain or other symptoms the person alleges, we will consider those symptom(s) in deciding whether the person’s impairment(s) is severe. If the person’s pain or other symptoms cause a limitation or restriction that has more than a minimal effect on the ability to perform basic work activities, we will find that person has a severe impairment(s).”

In Step 3 the SSA considers whether the person’s impairment is found on the Agency’s “Listing of Impairments” or has an equivalence in severity to any of the Criteria of an impairment on the List. FM is not on the Listing of Impairments, but could have equivalence, for example, to inflammatory arthritis. But in a majority of cases equivalence is not found, so the process must continue to Steps 4 and 5 which involve a *Residual Functional Capacity* assessment.

Residual Functional Capacity: “We consider the severity of the impairment...and whether the impairment prevents the person from doing his or her past relevant work or other work that exists in the national economy.”

“We base our RFC assessment on all the relevant information in the case record. We consider all the effects of all the person’s medically-determinable impairments, including impairments that are ‘not severe’. For a person with FM , we will consider whenever possible because the symptoms of FM can wax and wane so that a person may have ‘bad and good days’”.

“We use our RFC assessment to determine whether the person is capable of doing any past relevant work (step 4) or any other work that exists in significant numbers in the national economy (step 5). If the person is able to do any past relevant work, we find that he or she is not disabled. If the person is not able to do any past relevant work or does not have such work experience, we determine whether he or she can do any other work.”

The Ruling recognizes “that widespread pain and other symptoms associated with FM, such as fatigue, may result in exertional limitations that prevent a person from doing the full range of unskilled work in one or more of the exertional categories...People with FM may also have non-exertional physical or mental limitations because of their pain or other symptoms.^[24] Some may have environmental restrictions, which are also non-exertional.”

Further, “Adjudicators must be alert to the possibility that there may be exertional or non-exertional (for example, postural or environmental) limitations that erode a person's occupational base sufficiently to preclude the use of a rule in appendix 2 to direct a decision.”

These latter two qualifiers recognize the further limitations on a person’s ability to work and should be documented by physicians or other qualified professionals.

APPENDIX IV

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

This Appendix includes the following:

1. Memo from Bernard A. Kansky, Esq.: Recommended Documentation of CFS Disability to be submitted to Social Security and/or for Private or Employer Disability. Based on Attorney Kansky's extensive experience adjudicating ME/CFS cases, the Memo details the specific documentary evidence that should be submitted to Social Security (and other disability carriers). Following the Memo's suggestions should definitely strengthen a claimant's case.

The Memo provides very useful and helpful suggestions to Doctors on the type of documentation to include in the Medical Report. Moreover, **the Memo also includes the actual legal language** that would be helpful for the Doctor to use in documenting your disability. Give your doctor(s) a copy of the Memo.

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

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

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

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

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

5. Incapacity Checklist: This checklist can help in evaluating your inability to work. You may

give a copy of this checklist to your doctor to assist him/her in preparing your medical report.

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

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

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

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

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

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

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

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

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

(a) The medical history.

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

(c) An indication of *regular* visits, and the frequency thereof. (If the claimant is totally disabled, both Social Security and the Long Term Disability Carrier expect the Claimant to

maintain regular medical visits).

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

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

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

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

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

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

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

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

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

(h) The medical opinion, if truthful and correct, to the effect that the patient has been totally and permanently disabled by reason of the unpredictability of the frequency and severity of his/her multiple physical symptoms since the date of onset, and for not less than twelve consecutive months; and in any event, for the foreseeable future in that at present,

there is no known treatment, cure or management program for this disease. The Claimant is unable to engage in, and more importantly, sustain, any gainful employment activity, even light part-time, sedentary work from home.

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

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

Checklist of ME/CFS Symptoms

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

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

1. Most common symptoms

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

2. Psychological symptoms

- Depression (70-85%) (*reactive or secondary depression*)

- Anxiety (50- 75%) (*including panic attacks and personality changes*)
- Emotional lability (mood swings)
- Psychosis (1%)

3. Other nervous system symptoms

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

4. Other symptoms:

- Pharyngitis (50- 75%) (*inflammation and discomfort of the pharynx*)
- Dyspnea on exertion (*labored breathing or hunger for air*)
- Worsening of premenstrual symptoms (70% of women)
- 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 and/or Disabling ME/CFS Symptoms

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

14. Check for clonus
15. Signs of Romberg
16. Crimson crescents to the sides of uvula
17. Check for low-grade fever
18. Brain scan

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

EXCERPTS FROM OLDER CFS SOCIAL SECURITY DOCUMENTS

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

Medical History

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

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

Laboratory Test Reports:

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

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

Information About Function: Statements/opinions from the treating source(s) about the impact of the individual's impairment on his/her ability to function in day-to-day activities of living are of great value to SSA in making its determination as to whether or not the

individual is disabled. In this regard, any information the treatment source is able to provide contrasting the patient's medical condition and functional capacities since the onset of CFS with the patient's status prior to CFS is meaningful to SSA's evaluation.

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

Incapacity Checklist

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

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

How does your condition affect:

- your daily activities
- your ability to stand, sit, or walk for a long period
- your ability to lift or carry weight
- your ability to understand, carry out, and remember instructions
- your ability to respond appropriately to your supervisor and co-workers
- other physical or psychological functional restrictions, and
- your ability to adjust to the stress of a work environment

Sample Doctors' Letters

This section includes a selection of sample doctor's letters that were actually written to Social Security to document patients' ME/CFS disability claims. These letters – Disability Reports -- are provided to help show how a doctor's letter should be written and the type of

information it should contain in order to make the letter strong and effective.

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

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

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

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

Explanation to Letter #1

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

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

The letter also provides the required assessment of the patient's inability to work and to perform

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

Letter #1

To Whom It May Concern:

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

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

(_____)'s physical symptoms have exacerbated since my last letter to your office and this illness has proved to be emotionally devastating. She is 100% disabled at this time. Work for her is totally out of the question.

I will continue to follow (_____) to investigate therapies to counteract the

devastating illness.

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

Sincerely, (_____ MD)

Explanation to Letter #2

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

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

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

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

You should explain to your doctor the type of detailed documentation that s/he should include in the letter -- by doing so you will help your doctor help you. Most doctors will be glad to know how to write a stronger and more effective letter. One suggestion is to ask your doctor to let you see his or her letter (and the Social Security questionnaire) before they are mailed to Social Security. If the letter or questionnaire isn't strong enough, then you can ask your doctor to consider revising it based on your suggestions.

LETTER #2

To Whom It May Concern: (_____) is a patient under my care at the University of Massachusetts Medical Center. She is a 20 year-old female who for the past 2 1/2 years has had an illness characterized by marked fatigue, headaches, and extreme difficulty thinking and concentrating. In addition, she complained of enlarged left cervical lymph nodes and a sore throat. Laboratory studies show no other etiology for patient's illness. It appears that the patient has the chronic mono-like illness or as it is now called the chronic fatigue syndrome. This is a diagnosis of exclusion. It is clear in my mind that the patient is disabled from this illness and unable to work. It is difficult to predict the course of the illness, but only 20% of

patients spontaneously get better. However, with future therapies, the results may be brighter. At present, (_____) is clearly disabled from her illness and is unable to work.

Sincerely, (_____), MD

Explanation to Letter #3

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

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

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

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

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

Letter #3

RE: _____

DOB. _____

Dear Sir:

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

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

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

book, turning pages, winding a clock or watch, sweeping the porch, opening and closing windows, opening milk cartons, managing wall plugs, using a spray can, opening doors with keys. She is unable to write for fifteen minutes, shuffle and hold a hand of cards, care for her garden.

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

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

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

Sincerely yours,

M.D.

Date

EXPLANATION OF LETTER # 4

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

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

To whom it may concern,

I am writing today to provide a comprehensive disability report regarding my patient:

_____ who has applied for disability benefits. I first evaluated:
_____, and have seen her on _____ occasions since.

Ms. _____ has seen a number of physicians and health care providers since the onset of her various medical illnesses and conditions, but in some cases the concentration was on the current and most troubling issue. Therefore, at this time, I want to address all her issues in this letter in more depth and the manner in which they interact and compound one another.

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

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

Hers clinical presentation fits the American College of Rheumatology's criteria for the diagnosis of fibromyalgia. She was referred to Dr. _____ who confirmed this diagnosis. However, the rest of her symptoms, her decline in function and lower threshold for any activity raised suspicion of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), particularly after they all began after a viral infection in (month/year).

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

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

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

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

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

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

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

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

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

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

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

Some days she has very poor concentration and problems with short-term memory and issues with word retrieval. I have encouraged her to remain as active as possible as she can when she is able, but the unpredictable nature of her CFS combined with her fibromyalgia and Osteoarthritis maker her unable to work on any consistent and predictable basis. She requires numerous rest periods between minor daily activities and frequent trips to the bathroom when her bladder inflammation flares.

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

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

Helping Your Doctor Prepare the Medical Report

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

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

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

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

The Mass Disability Law Center in its booklet, *"How to Secure and Protect your Social Security Disability Benefits,"* suggests that patients should, if possible, ask their doctors and other providers to send them (the patients) copies of all the reports and documents to be submitted to Social Security. The patient him/herself could then submit the duplicate documents to Social Security -- after making copies of the documents for his or her own records. By this method the patient would make sure that Social Security would get all the records in a timely manner – just in case there are any delays in the physician’s submission of records.

There are two advantages to such a procedure:

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

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

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

Appendix V

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

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

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

Specific Suggestions on Preparing for the Social Security Hearing, from Attorney Bernard Kansky

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

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

Furthermore, Attorney Kansky recommends, if the patient suffers from no separate diagnosis of primary depression or no significant secondary depression related to the CFS that the doctor also include, if willing, the following paragraph in the updated medical report:

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

Bernard Kansky recommends that at the time the patient applies for the hearing, he/she begin to prepare the following exhibits, to be submitted to the judge approximately one month prior to the hearing date. In preparing these exhibits, as well as the pertinent hearing forms, the patient should collaborate in their preparation with a friend who also would be the person driving the patient to and from the hearing. The purpose of this collaboration is for the judge to understand that the patient needed help in preparing the forms and the exhibits; otherwise, the judge might speculate that the patient was capable of doing some work. Each exhibit should be prepared on separate pages, and all exhibits should end with the following phrase:

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

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

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

List of Exhibits the claimant should prepare:

a) Fill out the ME/CFS *Symptom Checklist*. Please complete, date and sign the list after checking symptoms. In filling out the form, you should include all important recurring symptoms produced by your illness. Generally, these will be symptoms that have lasted or recurred throughout your illness. (see Appendix IV for checklist)

b) *Claimant's Medications* -- complete, date and sign.

c) *Typical day in the life of (name)* from 8:00 A.M. one day to 7:59 A.M. the next day, in outline form on an hour-to- hour basis.

d) *Examples of episodes which highlight my cognitive dysfunction*. List some of the major examples of cognitive dysfunction which do not involve operation of a motor vehicle -- approximately 7-10 examples will be sufficient, also signed under the pains and penalties of perjury at the end.

e) *Why I am unable to do light part-time sedentary work from my home*. List the reasons why you are unable to perform:

(1) Word-processing and typing from your home;

(2) telemarketing from your home;

(3) stuffing envelopes;

(4) companion to the elderly;

(5) and child care from own home. Again, at the end, sign under the pains and penalties of perjury and date.

f) *List of activities formerly enjoyed*: Prepare a list of activities formerly enjoyed by you, which you are no longer able to do by reason of your total and permanent disability from CFS. Likewise at the end, please sign under the pains and penalties of perjury and date.

g) If you have no separate diagnosis of primary depression, nor any significant ongoing secondary depression already documented by your physicians, also prepare the following exhibit:

Why I am Not Depressed: Prepare on separate sheet or sheets of paper, a separate exhibit listing all of the reasons why you believe that you do not suffer any depression or mental or nervous condition which contributes to your total disability, likewise signed at the end, under the pains and penalties of perjury. **(Note: Please see Appendix VI for a discussion of the issues and**

problems, and pros and cons, of introducing a diagnosis of depression or mental impairment into a CFS disability application.)

If you do have mild anxiety or depression, which is normal for a chronic illness, you need not follow the above instructions – just don't bring it up. If your doctor says you are depressed and anxious about the illness, make sure your doctor states that the anxiety and depression are caused by the illness – and that in the absence of the physical illness, you would have no anxiety or depression.

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

Based on the experience and practice of Attorney Bernard Kansky of Boston, who has obtained a number of successful decisions for clients with ME/CFS from administrative law judges (ALJs),

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

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

5. The attorney should screen all reports, medical and otherwise, before such reports are forwarded (by the attorney) to Social Security or the ALJ. By so doing, any matter or language requiring clarification or correction can be discussed by the attorney with the provider. (Necessary changes in letters can be made before the letter is submitted.) Normally, if possible, the attorney will share the doctor's letter with the claimant before it is submitted to Social Security. This process also allows the attorney and client to cross-check necessary information. It may be easier and more timely for the doctor to give the letter to the claimant to get it to the Attorney. Or it may be easier for the doctor to send the letter directly to the attorney.

6. Prior to the hearing a vocational expert who has an understanding of ME/ CFS could test the claimant to determine his or her level of ability and stamina. As part of the testing process, the expert should arrange for the claimant to call several days after the conclusion of the testing to report the after-effects on the claimant's health resulting from the testing process. Often, following the rigors of testing, the claimant will be bedridden for several days. If this occurs, a notation to this effect in the vocational report is very useful.

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

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

a) A typical "day-in-the-life-of" description of the effects of the illness on daily activity;

b) A list of the medications taken;

c) A few events from the past year to a year and a half that highlight the claimant's cognitive dysfunction (but not involving the operation of a motor vehicle);

d) Why the client cannot even do telemarketing from his or her home. (This is a very good question for a ME/CFS patient since it shows the inability to maintain a schedule, i.e., the unpredictability of the illness. It also demonstrates the problem of cognitive dysfunction: the inability to maintain records; it may also show how the symptoms of sore throat and upper respiratory infection make talking difficult.)

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

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

Further Suggestions from Bernard A. Kansky, Esq. (who has handled a great many cases)

Letter to Ken Casanova, Re: Review of First Edition CFS Social Security Handbook

Dear Ken:

Had a chance to read your book for the first time this past Sunday. I thought it was well organized, and written clearly and concisely. If pressed for any "frosting on the cake," you might consider any one or more of the following supplements:

1. Maximize the relationship between the severity of the symptomatology and how it renders the claimant totally disabled.
2. Whenever a claimant appears before an Administrative Law Judge, it is my practice to have them driven there by a friend or family member - this helps reinforce the dependency upon others for such matters as grocery shopping, routine short-term travel, and most important of all, the key buzzword - "unpredictability" of onset of symptoms - if the Judge asks, "How did you get here today?"
3. In their appearance before the Administrative Law Judge, it is advisable for the claimant to have prepared in advance *a list* of their most frequent daily symptoms, how each symptom disables them, the usual extent to which it disables them, and most important, how any one or more of the symptoms can come upon them with little, if any, advance notice (resulting in the unpredictability factor, which renders claimants unable to maintain any viable work schedule, with any degree of regularity).
4. From a list prepared in advance, it is recommended the claimant give a brief synopsis of a "typical day in the life of the claimant." The use and need for notes to do this helps emphasize the short-term memory loss and cognitive dysfunctions from which claimants suffer.
5. It is preferred that if possible they keep their emotions partially, but not entirely, in check, to the extent they are able. If they are answering a question which to them is an emotional trigger, claimant should try to retain composure even if it takes an extra moment or so -- take a deep breath and relax -- and counsel should temporarily, if able, switch claimant onto a less emotional area of his/her disability, to help them regain composure and then field the question in a short while. This effort is usually appreciated and respected by the Administrative Law Judge.
6. Claimants should dress casually and comfortably wearing the same type of clothing they would wear around the house if, by way of example, guests were coming to visit them a few days after they have returned home from the hospital after a minor surgical procedure -- loose

pullovers, sweat pants, sneakers, etc., are fine as long as neat and clean. Claimant can even explain why generally they wear this style of attire -- because of the reduced effort it takes to dress themselves on those days when they are able to get up and out of bed.

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

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

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

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

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

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

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

Appendix VI

The Use of a Diagnosis of Depression or Other Mental Impairments in a ME/CFS Social Security Application

Introduction

The following section will review, in detail, the issues and problems of introducing a diagnosis of depression or mental impairment into a CFS disability application.

The purpose of this section is to acquaint the reader with the arguments for and against citing secondary depression or other mental impairments in an application.

One school of thought, previously, and perhaps still represented by some Legal Services disability attorneys is that the documenting of secondary depression or other mental impairment in a CFS application may aid acceptance of the disability claim.

The other school of thought represented here by Attorney Bernard Kansky is that the use of these diagnoses should be avoided, if possible.

This section also discusses the problems that can develop between attorneys and ME/CFS patients when mental impairments are used in disability applications.

As discussed below, there are only 3 bars to the inclusion of secondary depression in a CFS Social Security application: 1) poor documentation which allows the question of primary depression to surface, 2) the issue of stigmatization, 3) the issue relative to private disability: if the claimant is receiving, or might in the future receive private disability, **any question of depression might be used to curtail benefits**. If the issue of private disability does not enter into the picture, and a secondary depression due to ME/CFS is well-documented, the applicant must determine if physical signs and lab tests sufficiently establish the disability without the use of secondary depression. If not, the applicant might be well-advised to think carefully before rejecting the use of secondary depression as a means of establishing a ME/CFS claim.

A. The position that there is a positive use of secondary depression and mental impairment in a Social Security disability application

Obtaining Social Security disability benefits on a physical diagnosis alone can be difficult; although a well-documented, disabling physical diagnosis is often approved at the hearing stage. A physical diagnosis of disability is often more difficult to prove because of Social Security's use of the "GRIDS system" of disability evaluation. The "grid" is an evaluation tool: the claimant's diagnosis, age, employment history and work potential are plugged into the grid which then determines whether or not the claimant is disabled. Establishing even an obvious physical disability through the grid can be difficult -- unless the total physical disability is very well documented, claimants who are physically disabled are often rejected by the grid system. The claimant's disability application is then denied.

However, despite a rejection on a physical diagnosis alone by the grid, the patient will be given a "second chance" if the patient also has a mental impairment diagnosis, including a diagnosis of secondary depression (which is common in ME/CFS patients). With a mental impairment diagnosis, the claimant's disability is "taken off the grid," and the mental impairment diagnosis is

then added as an extra disabling factor. This additional step is often enough to tip the scale so that the patient's claim is approved.

A diagnosis of **primary** depression (unless clarified as a separate diagnosis from an existing ME/CFS diagnosis) may well negate a diagnosis of ME/CFS, and therefore cause a CFS disability claim to be rejected (since primary depression often looks somewhat like ME/CFS).

However, ME/CFS patients often suffer from secondary depression: the patient is depressed as a result of the physical illness. Secondary depression is a well-known side effect of many chronic physical illnesses.

If a physician, psychiatrist, or psychologist documents that a **depression is secondary**, then such documentation will usually add weight to a CFS disability application, and thereby make approval more likely.

As discussed in the next section, the possible drawbacks of using a mental impairment/depression diagnosis are 1) a possible future stigma which could attach to the patient, especially in the areas of employment or insurance; and 2) ***loss of employer-related, long-term disability benefits after two years.***

Some disability attorneys in Massachusetts have *believed in the use of mental impairment diagnoses (when such diagnoses are well-documented) as a necessary aid in gaining the acceptance of disability claims.*

Some attorneys generally have recommended further psychological testing whenever a patient's medical reports indicate a psychiatric or psychological diagnosis. The purpose of the testing is to determine and document any such diagnosis; the testing would then be submitted to Social Security as evidence of the diagnosis. These attorneys believe that looking at the whole person - physically and psychologically - is a proper and valid way of proving disability.

Special Note: For ME/CFS patients attempting to document neuro-cognitive symptoms, the best test is a neuropsychological test – not a neuropsychiatric test, nor generic psychological testing. However, neuropsychological testing on ME/CFS patients must be performed by a tester familiar with the illness. Do not use a tester who is not familiar with the illness – no test is better than a badly interpreted test.

Problems which may develop between ME/CFS patients and their attorneys regarding documentation or submission of mental impairment diagnoses

Historically, problems have occurred with the use of psychological testing by some legal assistance attorneys and other attorneys. Such testing may be properly used if there is already an indication in a provider's report of possible depression or mental impairment. Unfortunately, sometimes lawyers will routinely order the testing without prior documentation that there is a possible problem. In effect, the lawyer is engaging in a "fishing expedition" - to see if there is

any possible mental impairment that might be used on behalf of the client. Sometimes, the lawyer will routinely ask the client to submit to such testing during the initial client interview.

The results of such psychological testing may be accurate, consistent with a ME/CFS diagnosis, and helpful in obtaining approval of the claimant's disability. However, the results of psychological testing may sometimes present the patient with difficult problems:

- I. The testing may accurately reveal real psychological or emotional problems which the client may not wish to submit to Social Security because of possible stigmatization.
2. Sometimes psychiatrists or psychologists may make a false diagnosis. With an ME/CFS patient, such false diagnoses may consist of a) an erroneous psychiatric diagnosis as a substitute for the real ME/CFS diagnosis, or b) an additional, false psychiatric diagnosis.

A psychological report which falsely substitutes a mental impairment diagnosis for a ME/CFS diagnosis certainly will harm a CFS disability claim. Moreover, a false psychiatric diagnosis of any kind may itself cause real mental and emotional distress to the patient and lead to possible future stigmatization. The natural bias of some mental health professionals is toward finding mental health problems - even if they do not exist, or are minor, or are secondary to a physical illness.

In the past administrators who set policy for legal services disability attorneys in Massachusetts have clearly stated:

- a. That clients have the right to read all psychological reports that result from the testing - unless the tester indicates that the client should not see the report (not a usual procedure). In this case the attorney should tell the client to request permission from the tester for access to the report.
- b. That the client may veto submission of the psychological testing to Social Security. If the client does not want the report sent, the lawyer cannot submit it.

Still problems may sometimes develop. An attorney may believe that a report of psychological testing is vital to winning the client's case. The attorney may be concerned about the client's reaction to the report, or may feel the client doesn't need to see the report. For these reasons, and perhaps because the attorney is overworked, he or she may simply send in the report to Social Security without first giving the client the chance to read the report. If this happens, the patient may well feel betrayed by his or her lawyer; because of the loss of trust and feelings of anger, the patient will be in a difficult position: whether to continue with a lawyer s/he no longer entirely trusts or to change lawyers in midstream (an option which at times is not easily available).

Once psychological testing is performed by a qualified provider then the results of the testing may not properly be withheld from Social Security – and such withholding might be considered

fraudulent. Hence, if the attorney recommends such testing it is best to consider whether, given the possible difficulties, it should be performed.

As stated above, the use of psychiatric documentation of a secondary depression may actually help clarify a ME/CFS diagnosis, thereby increasing the client's chances of acceptance by Social Security. (Such documentation has proved helpful to CFS claimants.) Such clear documentation can, in the hands of a tester aware of ME/CFS, remove any doubts as to whether the depression is primary or secondary.

The alternate school of thought is that the use of a depression diagnosis can lead to stigmatization and is not necessary to winning if disabling physical symptoms are properly documented.

If an attorney recommends using a psychological diagnosis to support a disability claim, and the client is uncertain about submitting the diagnosis, the client should discuss his or her concerns with the attorney. The attorney may indicate that the case may be harder to win without the use of the psychological diagnosis. Or, if the attorney believes that the case cannot be won without using the diagnosis, the attorney may be unwilling to pursue the case unless the psychological diagnosis is used. After listening to the attorney, the client will have to weigh the risk of losing, against his or her reluctance to submit a psychological diagnosis. It may also be possible to obtain a second legal opinion.

However, there is a major difference between psychological/neuropsychiatric testing and neuropsychological testing. Neuropsychological testing performed by a tester knowledgeable about ME/CFS can measure organic cognitive dysfunction caused by the illness.

Cognitive dysfunction (memory loss, difficulty thinking, etc.) frequently affects ME/CFS patients. It is thought to result from the organic and neurological aspects of ME/CFS. Organic cognitive dysfunction does not fall into the categories of mental or emotional illness and therefore, does not carry their social stigma. **Neuropsychological testing** can distinguish between organically-based cognitive dysfunction and symptoms based on emotional or "psychological" illness. Neuropsychological testing, therefore, may aid in eliminating psychological diagnoses and in establishing an organically-based cognitive dysfunction associated with CFS (thereby supporting a CFS diagnosis). Moreover, neuropsychological testing can document various "non-exertional factors" such as the inability to concentrate, loss of memory functions, etc. which clearly interfere with the ability to work. The importance of correct interpretation of neuropsychological testing is paramount; **the tester must be familiar with how to interpret neuropsychological tests when the patient has ME/CFS**. The patient must ask the tester beforehand if he/she is familiar with ME/CFS, and if the tester can do the interpretation in a way that takes the illness into account. Sometimes, testers unfamiliar with ME/CFS can misinterpret the tests to the detriment of the ME/CFS diagnosis.

Under the GRIDS system of disability evaluation, anyone found capable of light work is usually not considered disabled. However, when there are non-exertional factors, the GRIDS system cannot be rotely relied upon, and non-exertional factors, if properly applied, can take the application off the GRIDS system.

Factors such as paying attention and concentrating on the job task, performing job activities within a schedule and at a consistent pace, maintaining a regular attendance and being punctual, remembering locations and work-like procedures -- all these additional factors are important in determining the ability to perform substantial gainful activity,

These non-exertional elements are often crucial to a CFS claim. Neuropsychological testing can be an aid in documenting these factors. Whether or not such testing is performed, it is vital that the patient's providers document neurological/cognitive symptoms and the effects of such symptoms on the patient's ability to work.

B. The case for avoiding, if possible, the use of depression or other mental impairment diagnoses in a ME/CFS disability application

Position of Attorney Bernard Kansky of Boston, Massachusetts: Attorney Kansky has obtained a number of successful decisions for ME/CFS claimants from administrative law judges.

1. The question arises as to the necessity of introducing a diagnosis of depression or mental impairment into the record of a CFS Social Security disability claimant as a means of increasing the odds of a favorable decision.
2. There are two types of depression: primary and secondary. Secondary depression occurs frequently in ME/CFS as a patient's reaction to long-term physical symptoms. Depression is a common secondary symptom of many chronic illnesses. Primary depression is considered a separate illness with its own causative factors.
3. Both ME/CFS and primary depressive illness have a number of common symptoms (but ME/CFS has certain symptoms that are not found in primary depression). By introducing a diagnosis of depression into a CFS claim, one easily begs the question of primary depression. The claimant may then be required to disprove the diagnosis, often having to run the gamut of consulting examiners who may further muddy the waters. Receiving disability for primary depression may be more difficult since the illness may be alleviated by the use of antidepressants. Therefore, a ME/CFS patient misdiagnosed as being primarily depressed may not receive disability.
4. This difficulty may be eliminated by a physician's statement that any depression is clearly secondary and dependent on the patient's physical illness (CFS). In some cases, letters from psychiatrists to this effect have actually enhanced a claimant's disability application.

5. However, according to Attorney Kansky, there are important reasons not to, unless absolutely necessary, introduce or develop a diagnosis of depression or mental impairment into a CFS disability application, even one of secondary depression.

6. The first reason is as follows: **under most private, employer-related disability policies**, there is a provision for completely terminating benefits after two years (for those under 65) if there is a finding that depression contributes to the individual's disability. Any such attempt to terminate benefits on these grounds may be challenged by means of a physician's report stating if ever, in the future, the patient were relieved of all his/her physical symptoms, then there would be no primary or secondary depression that would prohibit the claimant's return to gainful employment activity - in other words, the depression would not contribute to any continuing disability. Introducing a diagnosis of depression can jeopardize the long-term financial interest of anyone receiving, or in a position to receive, long-term disability benefits. Such diagnoses should clearly be avoided in a Social Security disability claim of a person receiving employer disability benefits (or for a person who potentially might receive such benefits). Note: as of 2021, some insurance companies had previously introduced new policies for “subjective” illnesses such as ME/CFS with maximum benefits of two years only. In an individual case under such a policy, the mental impairment issue just discussed may not be at issue since the policy is for two years only.

Disability attorneys should fight any notion that ME/CFS is a “subjective illness” and introduce, for instance the 2015 U.S. Institute of Medicine Report which concludes the illness is objective and organic. Also the 2014 Social Security Ruling is an excellent document for this purpose.

7. The second reason to avoid mental impairment and depressive diagnoses (even a diagnosis of secondary depression) in a Social Security application and record is the potential for possible stigmatization. The diagnoses become part of a permanent government record; if an effective therapy for ME/CFS is found or if a patient goes into remission so that he may again work, the tag of depression or mental impairment may become an obstacle to future job and other opportunities. Social Security records are not entirely inaccessible.

8. Attorney Kansky believes that, in most cases of ME/CFS, use of the mental impairment or depressive diagnosis is not required to obtain a favorable disability finding. ME/CFS has up to 10 or 20 disabling symptoms which taken either by themselves or in combination are more than sufficient to prevent employment. Mental impairment diagnoses are not required in the presence of so many physical symptoms of such severity. An attorney who has sufficiently researched the illness and has familiarized him/herself with the client's physical symptoms and their disabling effect can assist a physician in preparing the medical report without introducing the depressive diagnosis.

9. Attorney Kansky tries to avoid introduction of these diagnoses, since he believes they are generally not necessary and could be a serious problem for the claimant in the future. To date, he has not found it necessary to introduce these diagnoses in order to obtain favorable decisions.

How to resolve the two different points of view above. An individual should listen to a prospective attorney's view of the issue, if it comes up. Then the individual will have to assess the attorney's opinion. The Mass. ME/CFS&FM Association can recommend experienced attorneys.

Appendix VII

Landmark Federal Court Decision Establishes Right of Persons Diagnosed with and Disabled by CFS to Obtain Social Security Disability Benefits

On November 30, 1993, the United States Court of Appeals, 10th Circuit, handed down a landmark court decision, establishing and enforcing the right of disabled individuals diagnosed with CFS to collect Social Security Disability benefits. The decision, *SISCO vs. the United States Department of Health and Human Services* (10 F.3d 739 [10th Circuit 1993]) constitutes an important recognition by the federal courts of the plight of ME/CFS patients. The decision will have the effect of requiring the Social Security Administration to more clearly recognize CFS as a legitimate disabling illness and will cause the Social Security Administration to award benefits more fairly and with less difficulty. The decision will be an important legal tool for attorneys and legal advocates in establishing CFS disability claims before Administrative Law Judges, and when necessary, before the federal courts. (Of course, since then, the 2014 Ruling has improved the understanding of CFS by the Social Security Administration.)

Unfortunately some States Disability Determination Services may not be fully aware of the 2014 Ruling, nor may even some Administrative Law Judges. The claimant's attorney and doctor should reference the Ruling in their briefs and letters.

Specifically, the ruling reversed the denial of Social Security benefits to a clearly disabled person suffering from CFS by an Administrative Law Judge and by a Federal District Court. The Appeals Court made two major findings with regard to Social Security Disability CFS Claims:

(1) The Court found that Social Security cannot deny a CFS Disability Claim because the CFS diagnosis cannot be definitively confirmed or verified by one or more laboratory tests. The Court found that, at the present time, there are no laboratory tests which can be used to establish or verify a CFS diagnosis. The Court found that the present medical consensus that CFS is properly diagnosed by a process of excluding other illnesses and by the presence of a characteristic symptom profile must be accepted by Social Security as the proper method for establishing a

CFS diagnosis. A diagnosis properly established by this method cannot be rejected by Social Security simply because laboratory tests are not available to definitively establish the diagnosis.

(2) The Court also determined that a physician's diagnosis of CFS which is based on proper diagnostic method cannot be rejected simply because, in the past, one or more of a patient's physicians have been unable to diagnose the patient's illness (particularly if the earlier failures to diagnose do not contradict the subsequent diagnosis of CFS.)

3) The Court recognized that CFS had only recently been validated by the medical community, and that in the past many physicians were not sufficiently informed to make a diagnosis. Moreover, the Court found that the Administrative Law Judge, contrary to the evidence presented, minimized the severity and the disabling effects of the patient's illness. The Court further found that the Administrative Law Judge distorted the patient's testimony. The findings of the Court, in this regard, will serve as an instruction to the Administrative Law Judges and the courts to evaluate CFS claims based on the evidence presented.

Sadly, after almost 20 years since the Ruling, there are ALJs as ignorant of the illness as in 1993.

Here follows some of the more pertinent language of the decision:

“The most glaring misconception is the ALJ's belief that the language in Paragraph 223(d)(5)(A) of the Social Security Act (SSA) requiring proof of a disability by “medically acceptable clinical or laboratory diagnostic techniques” means that a disability is covered by the Act only if it can be conclusively diagnosed by a "laboratory-type" test... Indeed, the plain meaning of the language simply indicates that a claimant's disability must be diagnosed through the use of a technique, either clinical or laboratory, that has been accepted by the medical community.

“At this point there is no "dipstick" laboratory test for chronic fatigue syndrome... Furthermore, since its "discovery" a few years ago, numerous cases involving chronic fatigue syndrome have been adjudicated across the country and we are unable to find any suggestion in these cases that this disease - or any other disease - is per se excluded from coverage because it cannot be conclusively diagnosed in a laboratory setting... “

“The "operational" diagnosis technique used by the medical community at the present time involves testing, the matching of a detailed list of symptoms, the painstaking exclusion of other possible disorders, and a thorough review of the patient's medical history... Although this type of clinical diagnostic method may not be as dramatic or impressive to a layman as a "dipstick" laboratory test, it is the technique presently used and accepted by the medical community. Section 223(d)(5)(A) of the Social Security Act does not require more...

“Moreover, because chronic fatigue syndrome is diagnosed partially through a process of elimination, an extended medical history of "nothing-wrong" diagnoses is not unusual for a patient who is ultimately found to be suffering from the disease... Finally, in a purely linguistic sense, an early report that, "I am unable to find the cause," does not contradict a later report that,

"I have now found the cause." These statements together demonstrate an evolution rather than a contradiction."

Additional federal court decisions granting CFS and Fibromyalgia disability claims:

1. *Rose v. Shalala*, 34 F.3d13(1st Cir. 1994) A landmark decision supporting the right of disabled persons with CFIDS to receive Social Security Disability benefits.

2. *Mongeluzo v. Baxter Travenol Long Term Disability Benefit Plan*, 1995 WL 34268 (9th Cir. (Cal.)) Important decision upholding CFS claim against employer disability carrier; carrier claimed that the person with CFS had a psychological disorder and was not entitled to continuing long-term benefits.

3. *Preston v. Secretary of Health and Human Services* 854 F. 2d 815 (6th Cir. 1988) Precedent setting decision upholding right of claimant with disabling fibromyalgia to collect Social Security disability benefits.

Appendix VIII

Disability Case Reviews

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

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

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

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

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

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

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

(Sometimes, a person will receive a "pre-review questionnaire" containing a few simple questions. This purpose of this form is simply to determine, by the answers to the questions, whether the person should be reviewed. For instance, if the person answers that they are improved, or that their doctor says they can work, then a review may be undertaken. If you receive such a form, answer the questions carefully and make sure they reflect the ongoing severity of your disability. If you have any questions, call the disability committee through "contact us" at the Massachusetts ME/CFS & FM Assn website. Also, if you are in any doubt that a review has actually begun, you should call Social Security and ask. If a review has begun, you must act.)

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

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

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

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

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

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

If, after the initial review, you are told that you have been found not to be disabled, you should appeal immediately in writing for reconsideration. You may have all your benefits continued until a decision on reconsideration, but only if you specifically request in writing that your benefits be continued and only if you do so within 10 days of the initial rejection decision. (You have 60 days to file for reconsideration, but if you want your benefits continued, you must act within 10 days.)

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

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

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

believed that you continued to be disabled. Moreover, Social Security can take ability to pay into account in seeking repayment.

Frequency of reviews:

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

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

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

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

Appendix IX

Other Disability Assistance Programs

I. Disability Insurance through Your Employer

Many employers offer their employees disability insurance which provides a disability income if the employee is unable to continue to perform his or her job. Generally, disability insurance through an employer is divided into two forms: a six-month *short-term disability*, which is then converted to a *long-term disability* if the employee continues to be disabled. Some companies do not offer a short-term disability, so the employee must utilize sick pay or a medical leave of absence while waiting to apply for a long-term disability. If you find that you can no longer work at your present job, and that a change or reduction in hours, or a move to a less stressful position within the company, will not enable you to continue working, then you should apply to the company for disability. In order to qualify for disability, you should apply while you still are employed; if you leave your job or are terminated, you may lose your right to disability insurance unless you had previously filed a claim while you were still employed. If you can prove you were disabled while you were still working, you may be entitled to receive benefits even if you apply after you are no longer working; however, it is still far safer to apply for benefits while you are still an employee.

Normally you will qualify for disability during the short-term period and during the first two years of long-term disability if you are unable to do your present job. However, under many *long-term disability* policies, at the end of two years the disability standard changes: you are eligible to continue receiving disability only if you are determined to be totally disabled, that is, you are unable to work at any employment. To qualify, you will have to obtain strong documentation of your disability from your physician. Your doctor will have to explain, in detail, how your diagnosis was arrived at, the severity and chronicity of your illness and its symptoms, and how the chronic and serious effects of your illness prevent you from working. Many long-term disability policies require objective evidence. Therefore, any tests which showed positive should be listed by your doctor in his report. See portions of this booklet that list relevant lab tests.

In order to be approved for short and long-term disability through your employer, you must have a physician who can medically document and verify your illness and disability. It is, therefore, necessary to develop and maintain an ongoing relationship with a doctor who understands your illness and disability and who will assist you in obtaining disability benefits. After you have been approved, you should continue to maintain a constructive, ongoing relationship with the physician since the insurance company will review your eligibility at yearly or shorter intervals. During these reviews the focused assistance of a physician who knows the history and severity of your disability can prove to be invaluable.

Many long-term disability policies permit the insurance company to terminate your disability benefits after two years if a mental impairment significantly contributes to your disability. Some insurance companies will seize upon any mention of depression in your medical record as a means of terminating your disability benefits at the end of the initial two-year period. Therefore, it is very important for a person with ME/CFS who is either receiving long-term disability benefits through an employer, or has a potential claim to: (1) make sure that a definitive diagnosis of ME/CFS is obtained so that there is no question of the validity of the ME/CFS diagnosis as opposed to the conflicting diagnosis of depression, and (2) to avoid, if possible, the introduction of a diagnosis of secondary depression into one's medical record. If your doctor insists upon documenting a diagnosis of secondary depression, do your best to make sure that your doctor clarifies such depression as secondary; that is, the depression is a direct result of your physical illness. Also, ask your doctor to state clearly that the depression would not exist in the absence of ME/CFS, and that the depression by itself would not prevent you from working.

Most insurance companies will require that you apply for social security disability benefits as a condition of receiving *long-term disability* benefits. It is in your interest to pursue your social security application seriously. If you are turned down by social security, the insurance company may use such a rejection to question whether you should continue receiving long-term disability benefits. On the other hand, if you are accepted by social security, the resulting determination by the government that you are totally disabled and unable to work at any employment will assist

you in making a strong case to the insurance company that your long-term disability benefits should continue after two years (when you must be totally disabled). Just as when you applied for your company disability, you should strive to prevent any mention of depression in your doctors' letters to social security. Your insurance company may attempt to use social security documentation of depression to terminate your long-term disability benefits. Again, if your doctor insists upon documenting depression, make sure that he or she clarifies such depression as secondary and caused by ME/CFS, that such depression would not exist without the ME/CFS, and that such depression by itself would not prevent you from working.

At times, either your employer or the insurance company may attempt to deny that your illness is disabling, or present obstacles to a timely evaluation of your claim, or attempt to reject your claim either directly or indirectly. In such cases, you should seek either the advice or assistance of an attorney who is familiar with such problems and who can represent your interests to the insurance company; and if necessary make use of insurance appeal procedures or other legal avenues. If you are encountering resistance in the processing of your claim or if *your* claim has been rejected, contact the *Mass Association at this website* for advice and suggested lawyer referrals. .

II. Disability Retirement Benefits for State Employees and Teachers

In addition to other disability assistance programs, if you are disabled and are employed by the Commonwealth of Massachusetts or a public school system, or any other employer which contributes into the State Retirement system, you may be eligible for *Disability Retirement benefits* if you have at least ten years of credible service and are either a veteran no older than 65, or a non-veteran younger than 55. To qualify for a disability retirement, you must “*be substantially incapable of performing your particular job, any similar job, or any other job for which your training and qualifications are suitable*”. If your application is approved, you will receive a disability pension. You are allowed to apply for a disability retirement *only* while you are still a state employee or teacher. Do not resign until you have filed an application for *Disability Retirement benefits*. The process of applying for *Disability Retirement benefits* is thoroughly explained in the pamphlet entitled *Disability Retirement Guide*, which is published by the Public Employees Retirement Administration of the Commonwealth of Massachusetts, 617) 367- 7770. Other states may also have similar Disability Retirement programs.

Addendum I

Plans for Achieving Self-Support While Receiving Supplemental Security Income (PASS)

What is a plan for achieving self-support?

Basically, a plan for achieving self-support, or PASS for short, is a plan for your future. Many people with disabilities want to work, and you're probably one of them. But maybe you need to go back to school before you can get a job. Or maybe you'd like to start your own business, but you just don't have the money. Whatever your work goal may be, a PASS can help you reach it.

A PASS lets you set aside money and/or other things you own to help you reach your goal. For example, you could set aside money to start a business or to go to school or to get training for a job.

If you're already getting Supplemental Security Income (SSI), having a PASS means you'll be able to keep more of your SSI payment each month. If you don't get SSI because your income or resources are too high, setting up a PASS may help you qualify. And that can be very important because people who get SSI usually get Medicaid, too.

How will a plan affect my SSI checks? Under regular SSI rules, your SSI check is reduced by the other income you have. But the income you set aside for a PASS doesn't reduce your SSI check. This means you can get a higher SSI benefit when you have a PASS. But you can't get more than the maximum SSI benefit for the State where you live.

Money you save, or things you own such as property or equipment, that you set aside for a PASS won't count against the resource limit of \$2,000 (or \$3,000 for a couple). Under regular SSI rules, you wouldn't be eligible for SSI if your resources are above \$2,000. But with a plan, you may set aside some resources so you would be eligible for SSI.

Who can have a plan?

You can, if you:

Get SSI (or can qualify for SSI) because of blindness or a disability; and

Have or expect to receive income (other than SSI) and/or resources to set aside toward a work goal. And remember: If you don't get SSI now, having a PASS may help you qualify.

What kinds of expenses can a plan help pay for?

A plan may be used to pay for just about any expenses that will help you reach your work goal. For example, your plan may help you save for:

Supplies to start a business;

Tuition, fees, books, and supplies needed for school or training; Supported-employment services, including payments for a job coach; Attendant care or child care expenses;

Equipment and tools to do the job; and

Uniforms, special clothing, and safety equipment.

These are only examples. Not all of these will apply to every plan. You might have other expenses depending on your goal.

How do I set up a plan?

Your plan must be in writing and approved by Social Security. This chart shows the steps you should follow to set up your plan.

1. Choose a work goal. The goal must be a job. It should be a job you're interested in doing and that you think you'll be able to do at the end of your plan.

2. Find out how long it will take to reach your goal. *Note:* A plan should not last longer than 3 years. But if your plan involves school or training, it may last up to 4 years.

3. Decide what things (such as training or tools) you will need to reach the goal. *Note:* Each person will need different things to reach the goal. For example, if you want to work in a restaurant, you may need training to learn how to cook. If you want to become a computer programmer, you may need a college degree and a computer in order to reach your goal. If you want to start a business, you may need to rent a store or office and buy equipment and supplies.

4. Find out the cost of the things you need to reach your goal.

5. Find out how much money you'll need to set aside each month to pay for them. Plan a way to keep receipts for the things you need. *Note:* If you're setting aside income, your SSI benefit will usually increase to help pay your living expenses. The people at Social Security can estimate what your new SSI amount will be if you set up your plan.

6. Make plans to keep any money you save for the goal separate from any other money you have. The easiest way to do this is to open a separate bank account for the money you save under your plan. But you don't have to open a separate account. Just be sure you can tell Social Security how you're keeping it separate.

7. Write the plan, sign, and date it.

8. Bring or mail the plan to your local Social Security office.

Who may help me set up a plan?

Anybody can help. You may set up a plan yourself or get help from: a vocational rehabilitation counselor; an organization that helps people with disabilities; an employer; a friend or relative; or the people at your Social Security office.

How do I write a plan?

There is no required form for a plan. You may simply write a letter that gives all the information about your plan.

What does Social Security do after I submit my plan?

After you submit your plan, Social Security will:

- review the plan to make sure it is complete;
- decide if there is a good chance that you can reach your goal;
- decide if any changes are needed and discuss those changes with you; and
- send you a letter to tell you if the plan is approved or denied.

If your plan is approved, Social Security will contact you from time to time to make sure that you are doing what your plan says you will do to reach your goal.

What happens if my plan is not approved?

If your plan is not approved, you have a right to appeal the decision. The letter you'll get will explain your appeal rights and tell you what you need to do to appeal. You may also submit a new plan to Social Security.

Can I change my plan after it is approved?

Yes. You must tell the Social Security office in writing what changes you want to make, such as a change in how much money you set aside each month or additional expenses you will have. The Social Security office will tell you whether the changes are approved. The changes must be approved in advance. It is very important that you tell Social Security as soon as possible about any changes that might affect your plan.

What happens if I cannot complete my plan?

If you cannot complete your plan, you may set up a new plan with a new work goal. If you don't set up a new plan, any money or other things set aside under the original plan may begin to count toward the \$2,000 resource limit. If they put you over the limit, you may become ineligible for SSI. Also, Social Security will begin to count the income you were setting aside under the plan. However, as long as you tell Social Security as soon as possible that you cannot complete your plan, you won't have to pay back any extra SSI you got while you were following your plan.

How will a plan affect other benefits I get?

You should check with the agency that is responsible for your other benefits to find out if the plan (and the extra SSI) might affect those benefits.

Are there any other rules that may help?

Yes. Other SSI rules may help you while you work. They can help you keep more of your SSI check, and they can help you keep your Medicaid. There are also some special rules for students. For more information, ask Social Security for the booklet, *Working While Disabled - How Social Security Can Help*.

For more information

If you want more information or if you want to make an appointment with a Social Security representative, just give them a call. Their telephone number is listed in your telephone book under "Social Security Administration" or "U.S. Government."

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