

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

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*Massachusetts CFIDS/ME & FM Association*  
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## **DISCLAIMER**

The Massachusetts CFIDS/ME & FM Association serves as a clearinghouse for information about Chronic Fatigue Immune Dysfunction Syndrome/Chronic Fatigue Syndrome (CFIDS/CFS), Myalgic Encephalopathy (ME) and Fibromyalgia Syndrome (also known as Fibrositis).

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

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## **HOW TO USE THIS BOOK**

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

Fortunately, I hope, this book is well-organized. The book is not meant to be read through entirely. You should use the Table of Contents to find what you need to know according to what step of the Social Security Disability process you are in.

If you want to know if you are potentially eligible to apply, start by reading the Introduction. If you decide to apply, then you must read the main body of the booklet after the Introduction, as well as Appendix II and Appendix IV. If you already have an up-to-date and well-documented CFS diagnosis, you may want to skip the section on “Obtaining a CFS Diagnosis.”

It is very important that everyone read, no matter what stage you’re involved in, the section on the **1999 CFS Ruling**, because it’s so important.

If your doctor needs help in knowing how to diagnose CFIDS or FM, give him/ her Appendix I.

If you reached the Administrative Law Judge hearing stage, turn to Appendix III. If you’re getting reviewed, turn to Appendix VI.

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

If you are applying for disability through your employer, read Appendix VII and Appendix IV. You should also look at the Resource Section.

You get the idea: **Navigate using the Table of Contents.**

Just to let you know. This booklet has been an ongoing project since the early 1990s. It contains the advice of lawyers, disability specialists, and the experience of many disability claimants. I can say, from the reports of patients with CFIDS, that it has helped many. I hope it helps you.

Ken Casanova

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## **INTRODUCTION**

### **Eligibility for Social Security Disability Programs**

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

*The two programs are:*

1. SSDI Social Security Disability Insurance
2. 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 65 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 accumulated up to 4 quarters. 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 2003, so your ten-year period runs from 1993 to 2003. If you earned 20 quarters in 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, call your local Social Security office and ask for your Personal Earning Benefit Statement (PEBES). Ask them to send you the computer printout of your earnings/work history.

Give the Social Security Employee the date you became unable to work, your age, and the period of years in which you must have earned your quarters. Ask him or her to calculate the number of quarters you earned during those years to see if you qualify for SSDI. (If you are only 1 or 2 quarters short, call the Disability Committee. It may still be possible for you to qualify.)

Your date of disability may not coincide with the date you apply for disability. People with 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 became disabled as close as possible to the date you actually stopped working. By doing so you do not lose quarters. Your date of disability is the date you

became no longer able to work according to the above definition. 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 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 2003. You only worked from 1991 to 1996, so you have exactly 20 quarters accumulated. However, to qualify, you must have accumulated the 20 quarters during the ten-year period immediately prior to your becoming disabled. If your date of disability is 2003, your ten-year period is 1993-2003; as a result, you would lose the quarters you earned from 1991-1993 and you would not have enough quarters to qualify. However, if you backdate your application to 2001, your ten-year period will be 1991-2001, and you will have enough quarters during the ten-year period to 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.

## **Financial Eligibility Standards for SSI**

If you do not qualify for SSDI because you do not have a sufficient number of quarters, you may still be eligible for SSI.

Unlike SSDI, there is no requirement that an individual earn a specific number of quarters within a required number of years. In fact, a person who is disabled and has never worked may qualify for SSI.

However, SSI is a “low-income” program: to qualify an individual may have only very limited assets and monthly income.



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

<b>Maximum Property Value That a Disabled Person Can Own and Still Be Eligible for the SSI Program</b>		
<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.

These figures are for 2003 and will change at the beginning of each calendar year. 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.

In 2003, for a single person living alone, the SSI monthly flat payment was approximately \$666.38. Therefore, if your monthly income is substantially above this figure, you would not be eligible.

(Remember, a spouse's income counts as your income.) If you qualify for SSI, you will receive Medicaid medical insurance from the date of disability (no two-year waiting period).

**SSI for children:** If your child has CFIDS, 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. Those PWCs (persons with CFIDS) 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 CFIDS diagnosis and your inability to work. Because the program is new, the medical standards for approving a CFIDS disability are not yet clear.

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, you can receive two booklets explaining eligibility, application process, and program benefits by calling the MCLE at 1-800-966-6253 and ask for the booklets on the EAEDC program.

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. The phone numbers of the local legal services offices in Massachusetts are listed in the booklets put out by Mass. Law Reform on EAEDC.

### **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 1-800-645-8333 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. In Massachusetts call 1-800-632-8175 to find out how to apply for fuel assistance. (This program may be terminated in the near future.)

## **HOW TO APPLY FOR SOCIAL SECURITY BENEFITS IF YOU HAVE CHRONIC FATIGUE SYNDROME (CFS/CFIDS)**

### **I. The Application Process**

People with CFS who are applying for Social Security benefits should know that the application process could 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 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 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 call the Mass. CFIDS/ME & FM Disability Committee, or your local legal assistance office. 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 should 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 disability cases.

If you are 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 low income, the Mass. CFIDS/ME & FM 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, and cannot exceed \$4,000. The final attorney's fee is determined by Social Security. You should always obtain a *written* fee agreement if you have a private attorney.

If you are receiving benefits from an employer-related disability policy, the insurance company may be willing to pay the cost of an attorney.

Counselors are encouraged to obtain the names of any attorneys that applicants endorse as having helped them. The Mass. CFIDS/ME & FM Disability Committee can then develop a lawyer referral list to assist Mass. CFIDS/ME & FM Association members. If you need help with a lawyer referral, the Mass. CFIDS/ME & FM Disability Committee may be able to assist you. Call Ken at: (617)522-5835.

## **III. When To Apply for Disability**

To be eligible for Disability (SSDI or SSI), a person with CFS must no longer be able to do even light, sedentary, part-time work, on any continuing 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 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 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 requirement.

To properly pursue your application, you and your doctors must document as fully as possible your diagnosis of CFS. Proper diagnosis of CFS, according to the Centers for Disease Control guidelines, requires that the symptom complex must have lasted for at least six months. Therefore, until you have been sick for close to six months, it will be difficult for your doctor to confirm a 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. (This diagnosis requirement has no relation to your employment status - in other words, you can count six months of illness for diagnostic purposes while you were still working, before you apply for disability.)

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 CFS, 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: *Mass. CFIDS/ME & FM Disability Committee* (617) 522-5835.

#### **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.

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. However, in addition to these submissions, you should ask at least one of your doctors (often your primary care physician) to write a comprehensive medical report (letter) documenting, in detail, how your diagnosis was made. All your medical signs, symptoms, and

lab tests should be detailed. Secondly, your doctor should document the physical and cognitive limitations that prevent you from working. **The new Social Security Ruling on CFS (1999, see below)** specifically lists medical signs and lab tests which, when possible, should be documented. When the listed signs and lab tests cannot be provided, make sure to include all the signs, symptoms, and lab tests consistent with CFS.

The Ruling requires doctors to back-up their documentation of medical signs/lab tests/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.**

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 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) Letters which fully establish and document both the CFS diagnosis, and the patient's inability to work. These letters will be from the primary care physician or from a specialist who is in a position to provide the necessary information. Included with such letters should be the results of tests taken by the doctor which provide support for the CFS diagnosis. These letters should also document specific treatments undertaken (including use of medications) as well as the results of such treatments.

2) The second type of letter - which acts to supplement the comprehensive letter described above - 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 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 would 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, 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 has 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.

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

## **Letters from your Primary Care Physician**

We will deal first with the primary doctors' letters, which should fully establish and document your 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 CFS* and who is willing to write such a comprehensive letter. By reading these instructions you will be able to explain to your doctor what his/her letter should contain to best support your application. If you can obtain this type of comprehensive letter from more than one doctor, you should definitely do so.

If you would like information that would help you better communicate with your doctor and establish a more productive patient-physician relationship, Mass. CFIDS/ME & FM can provide you with an information packet. Call or write to obtain this information.

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

Apparently, individuals with a diagnosis of fibromyalgia have greater difficulty than those with chronic fatigue syndrome in obtaining approval of their claim for social security benefits. Many medical authorities are of the opinion that 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 he or she could also obtain a diagnosis of CFS. 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 CFS diagnosis by consulting a doctor familiar with CFS such as an Infectious Disease Specialist.

## **Obtaining a CFS Diagnosis**

Note: Patients who already have obtained a full diagnosis by a physician familiar with the proper diagnosis of CFS may want to skip onto page 999, since this section explains the comprehensive method of diagnosis according to the 1994 CFS Centers for Disease Control diagnostic criteria recognized by Social Security. However, for those patients still needing a diagnosis, this section will fully inform you as to the recognized method. All CFS patients applying for Social Security should at least be familiar with the diagnostic criteria.

To successfully apply for Social Security Disability benefits, an applicant should obtain a medically recognized diagnosis of his or her disabling illness or condition. In December, 1994, the U.S. Centers for Disease Control issued new guidelines for the medical diagnosis of Chronic Fatigue Syndrome. The new diagnostic criteria are contained in an article, "The Chronic Fatigue Syndrome: A



Comprehensive Approach to its Definition and Study," published in the *Annals of Internal Medicine*, December, 1994 (see Appendix 1 for entire article.) The new diagnostic criteria are intended to replace the former diagnostic criteria published in 1988.

The new criteria were designed to provide a formal, internationally-recognized method for the diagnosis of CFS. Over time, the new diagnostic criteria will gain weight among doctors, insurance companies and government agencies as a favored standard for evaluating and documenting a CFS diagnosis. However, the guidelines were specifically developed for research purposes; in order to maintain research clarity, a small minority of CFS cases will be excluded under the new definition. However, the new guidelines themselves state, "However, none of the components including the revised case definition can be considered definitive." In other words, a doctor who is well informed about CFS can still make a CFS diagnosis even if the new guidelines exclude such a diagnosis. (Necessary advice on gaining a diagnosis for a CFS case excluded by the new guidelines is provided below.) Generally, however, under the new guidelines, many cases of CFS will be more easily diagnosed than would have been possible under the 1988 guidelines. (Note: please see Appendix 1 for a note on the new 2003 Canadian CFS/ME Diagnostic Criteria.)

Under the new 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 new 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 CFS in obtaining a diagnosis and in applying for Social Security. By understanding the potential pitfalls of psychiatric evaluation, an informed individual with 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.

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 IV.

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 CFS sufferer. Many 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 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 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.

Routinely doing other screening tests for all patients has no known value (20,30). However, 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 next two paragraphs (from the CDC definition) go on to state that, presently, except for the purpose of specialized research there are no further recommended tests for the diagnosis of Chronic Fatigue Syndrome:

The use of tests to diagnose the chronic fatigue syndrome (rather than to exclude other diagnostic possibilities) should be done only in the setting of protocol-based research. The fact that such tests are investigational and do not aid in diagnosis or management should be explained to the patient.

In clinical practice, no additional tests, including laboratory tests and neuroimaging studies, can be recommended for the specific purpose of diagnosing the chronic fatigue syndrome. Tests should be directed toward confirming or excluding other etiologic possibilities. Examples of specific tests that do not confirm or exclude the diagnosis of the chronic fatigue syndrome include: serologic tests for Epstein-Barr virus, retroviruses, human herpes-virus 6, enteroviruses, and *Candida albicans*; tests of immunologic function, including cell population and function studies; and imaging studies, including magnetic resonance imaging scans and radionuclide scans (such as single-photon emission computed tomography and positron emission tomography) of the head.

Here the CDC clearly recommends that for the general clinical diagnosis and management of CFS, physicians and patients should not seek more specialized testing (except to exclude other possible illnesses). Despite these recommendations, Social Security, recently, has placed some emphasis on the use of "objective laboratory testing" in order to confirm a CFS diagnosis. Therefore, any more specialized testing available to a CFS applicant which demonstrates abnormalities consistent with a CFS diagnosis would be helpful in obtaining Social Security. However, such specialized testing, as the

guidelines make clear, is not available to most CFS patients and is not required to obtain Social Security benefits.

***The second phase of the diagnostic process*** may be called the *Exclusion/inclusion Phase*. In this 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 and 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)<sup>2</sup>] 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 nonmelancholic 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 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 postexertional 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. (**See 1999 CFS Ruling below.**) 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.

A final note on the new diagnostic criteria: The new criteria represent a major improvement over the 1988 criteria except in the case of a number of exclusions (discussed above) - this portion of the guidelines represents a partial set-back. Despite the fact that the guidelines should not be considered the final word on diagnosis (in the case of the exclusions discussed above), the limitations of the guidelines may not be understood by many doctors, insurance companies and some individuals and agencies administering disability programs. The new guidelines to some degree will gain influence as the primary and authoritative method for obtaining a diagnosis. Certainly the new guidelines will gain some influence with Social Security; however, individuals who have CFS but are excluded under the new guidelines will still likely be accepted by social security disability as long as their doctors provide sufficient medical documentation to confirm a CFS diagnosis and a resulting disability. In such circumstances the diagnostic method would be to evaluate according to the new 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 also find the following 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 II.)

## **Documenting the CFS Diagnosis to Social Security**

On April 30, 1999, the Social Security Administration issued a critical new Ruling: "**Social Security Administration Ruling, SSR 99-2p.; Titles II and XVI: Evaluating Cases Involving Chronic Fatigue Syndrome (CFS).**" This Ruling explains, in detail, the specific documentation necessary to successfully establish a Social Security claim for CFS. The Ruling lists the specific medical signs, symptoms, and laboratory tests to establish a CFS diagnosis.

Important: In addition to the listed medical signs and laboratory tests, the Ruling clearly states that other signs, symptoms, and laboratory tests **not listed** may be used to document a CFS disability. In using this booklet, you should first attempt to document your CFS disability according to the listed requirements of the new Ruling. If you are unable to document any or more than a few of the listed requirements, then you and your physician(s) should as fully, and in as much detail as possible, document your CFS according to the information and material in this booklet. The new Ruling also

explains how to document your inability to work, as well as your limitations in daily life. Please note carefully, in the following section, the **importance of frequent doctors visits and the charting of signs and symptoms during these visits.**

Please be aware that the new Ruling establishes the most current disability requirements for CFS. Therefore, some of the information in this booklet has been superseded by the Ruling. However, even when an individual is able to qualify strictly according to the letter of the Ruling, much of this booklet's information can be as a means of explaining how to more specifically document the CFS disability according to the Ruling. The booklet's material will be even more important to those who must take advantage of the Ruling's allowance of unlisted findings and tests **"which are consistent with medically accepted clinical practice and consistent with other evidence in the case record."** The material in this booklet has been developed over a period of years and so should be helpful in establishing a case when unlisted tests and findings are needed. When dated information in this booklet is clearly at variance with the Ruling, the instructions of the Ruling should be followed.

**Social Security Administration issues a major new ruling affecting all CFIDS Disability claims and reviews.**

On April 30, 1999, the Social Security Administration issued an extremely important new ruling.

## **"Social Security Ruling, SSR 99-2p.; Titles II and XVI: Evaluating Cases Involving Chronic Fatigue Syndrome (CFS)."**

### **Overview of the Ruling:**

This ruling sets new and more specific requirements for the medical evidence and documentation necessary to succeed in obtaining disability benefits or in maintaining one's benefits after a review. The new ruling is an attempt to clarify more specifically how Social Security examiners and adjudicators should evaluate CFS claims and reviews.

**The ruling explains exactly what medical evidence doctors should submit and how they should submit it; what laboratory tests will establish a case of CFS; and what documentation doctors, patients and others should provide as evidence of the patient's inability to work.**

Until this ruling, the guidelines for evidence and documentation necessary to establish a disability claim have not been clearly spelled-out; the new Ruling is an effort to give examiners clearer rules and guidelines for deciding on claims and reviews. The new Ruling is binding at all stages of the disability process: initial application, reconsideration, and administrative law judges -and it applies when SSDI recipients are periodically reviewed.

The new Ruling, without doubt, will become "the book" by which agency staff approve or disapprove claims and reviews. On the one hand, doctors and patients may find it more difficult to submit acceptable evidence, since the Ruling has limited the listing of CFS medical findings and laboratory tests -- examiners will often want to stick narrowly to the specified listing. **On the other hand, the Ruling does leave open the use of unlisted findings and tests "which are consistent with medically accepted clinical practice and is consistent with other evidence in the case record."** So patients, their doctors and attorneys will likely find themselves pressing



examiners and judges to accept evidence which is valid but not specifically listed.

All the difference will be made on how rigidly or flexibly Social Security implements the guidelines and whether or not the CFIDS community both works with and presses Social Security to assure reasonable flexibility. Unfortunately the Ruling has the potential to make it tougher for disabled CFS patients to obtain or maintain their benefits. As ever, as CFIDS patients, we face a changing situation; we simply and calmly will have to work with this new situation to make it better.

### **Establishing CFIDS as a Medically Determinable Impairment:**

The following is a summary of the Ruling. The evaluation of a claim or review consists of a series of steps or hurdles, each of which must be cleared in order to successfully obtain approval of benefits or of a review.

The first hurdle the CFIDS patient must clear is obtaining a finding that he or she has a "medically determinable impairment." In other words, the patient must, to Social Security's satisfaction, prove he or she has CFIDS. How is this done? The Ruling states: "CFS constitutes a medically determinable impairment when it is accompanied by medical signs and symptoms and laboratory findings." The Ruling notes that under the CDC case definition a person may be diagnosed on the basis of reported symptoms alone. However, this level of diagnosis is not acceptable to Social Security; to document a CFS diagnosis, verifiable evidence of more objective signs and symptoms must be submitted.

To clear the first hurdle -- establishing CFIDS as a medically determinable impairment -- specific medical signs and laboratory findings must be submitted. The Ruling next lists the signs and findings it will accept, but not before stating, fortunately for patients, "...the medical criteria below are only examples of signs and laboratory findings that will establish the existence of a medically determinable impairment...[medical research may find] additional signs and laboratory findings...the existence of CFS may be documented with medical signs and laboratory findings other than those below, provided that such documentation is consistent with medically accepted clinical practice and is consistent with the other evidence in the case record."

Doctors providing medical evidence for CFS patients will have to explain and justify the use of other medical signs and laboratory findings in supporting their patients' applications.

### **Medical Signs and Symptoms:**

The Ruling then lists medical signs: "...one or more of the following medical signs clinically documented over a period of at least 6 consecutive months establishes the existence of a medically determinable impairment for individuals with 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;

The Ruling here notes the overlap of symptoms between CFS and Fibromyalgia: "but individuals with CFS who have tender points have a medically determinable impairment."

The ruling also notes the overlap, and therefore the need for further diagnostic differentiation, among CFS, Gulf War Syndrome, Multiple Chemical Sensitivity and Depression.

I will discuss below the type of documentation of medical signs the Ruling requires physicians to provide, but note especially here that the Ruling requires documentation in the clinical record of signs over at least 6 consecutive months.

### **Laboratory Findings:**

Next, the Ruling lists laboratory findings that, if found, "...establish the existence of a medically determinable impairment in individuals with CFS." The Ruling does provide flexibility: "It should be noted that standard laboratory tests in the 'normal' range are characteristic for many individuals with CFS, and should not be relied upon to the exclusion of all other clinical evidence..."

The issue here is the extent to which examiners will heed this cautionary directive.

The listing of acceptable lab tests is as follows:

\*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 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;

\*Other laboratory findings("medically accepted clinical practice and consistent with other case evidence"), for example:

+abnormal exercise stress test

+abnormal sleep study

The EBV titer threshold numbers are so extremely high as to have no diagnostic purpose for selecting cases of CFS. One can only wonder as to why those constructing the ruling chose these numbers.

Only in a percentage of CFS patients will MRI brain scans 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.

A proportion of CFS patients have neurally-mediated hypotension. Research has not yet determined if this is a low or high proportion. According to Johns Hopkins researchers, protocols for correct use of the tilt table test in CFS are not widely followed --there is also disagreement as to which protocols are diagnostic.

Tilt-table tests are expensive and may not be reimbursable. Patients seeking the test would have to receive the test from a physician following reasonable protocols. Clearly, in the near future, only a minority of patients will have access to proper testing. Yet patients, in an attempt to document their CFS, may feel forced to try to obtain the test. The Ruling does allow for an alternative test 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.

The exercise stress test may or may not be abnormal in a CFS patient. Sleep studies are, perhaps, the test most likely to be abnormal, but again this test may not be accessible to many patients.

Overall, the lab tests listed will be difficult for most CFS patients to obtain and will not be diagnostic in a substantial percentage of cases.

### **Cognitive and Mental Findings:**

Next, the Ruling lists mental findings that will establish a case of CFS as medically determinable. These findings fall within two diagnostic categories: neurocognitive impairment and mental disorders. Symptoms of neurocognitive impairment include the familiar cognitive symptoms: memory problems, visual-spatial difficulties, calculation, concentration, etc.

The Ruling states "...when ongoing deficits in these areas have been documented by:

\*mental status exam (a medical sign)

\*psychological testing (a laboratory finding)

[Such findings] ...establish a medically determinable impairment. "

It is widely known that neuropsychological testing, as opposed to psychological testing, is the proper tool for diagnosing CFIDS. General psychological testing can be misleading diagnostically. Moreover, neuropsychological testing will only be diagnostically helpful in the hands of an experienced tester familiar with 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.

The Ruling further states that individuals with CFS may show medical signs which indicate a mental disorder, such as anxiety or depression. When such signs are adequately documented, a medically determinable impairment is established. In cases of CFS, patients often are anxious or depressed as a result of their illness (secondary depression). In these cases, medical findings would be diagnostic if correctly interpreted as connected to and confirming CFS. Such findings, however, in the past, have been used to negate a CFIDS diagnosis in favor of "psychological" illnesses.

**Documenting Medical Signs and Symptoms and Laboratory Findings:**

The ruling clearly states that, "appropriate documentation should include a longitudinal clinical record of at least 12 months prior to the date of application, unless the alleged onset occurred less than 12 months in the past... [moreover] the record should contain detailed medical observations, treatment, the individual's response to treatment, and a detailed description of how the impairment limits the individual's ability to function over time."

("When the alleged onset of disability secondary to CFS occurred less than 12 months before adjudication, the adjudicator 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 treatment and response to treatment as well as any medical source opinions about the individual's prognosis at the end of 12 months are helpful in deciding whether the medically determinable impairment(s) is expected to be of disabling severity for at least 12 consecutive months...)

**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 limits 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 CFIDS 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.

**Severity of the Illness:**

Once a case of CFS is found to be medically determinable, then the illness's severity (the second hurdle in the process) must be established. Severity is determined by the totality of medical signs, symptoms, and laboratory findings and the effects of the impairment on the ability to function. The adjudicator proceeds to evaluate the intensity and persistence of the symptoms. In making a determination of severity, the adjudicator will evaluate the patient's allegations of pain, fatigue, symptoms of neurocognitive problems, and other CFS symptoms. If the CFS symptoms are found to cause "...a limitation or restriction having more than a minimal effect on the individual's ability to perform basic work activities. the adjudicator must find that the individual has a 'severe' impairment." The Ruling also notes that individuals with CFS who have psychological manifestations related to CFS should be evaluated as to the severity of these symptoms in relation to the severity of a "listed mental disorder. "

**Documenting the PWC's (person with CFIDS) Inability to Work:**

Since CFS itself is not on the Listing of Impairments (subpart p of 20 CFR 404) and the finding of severity equivalence between CFS and a listed impairment is problematic, most CFS cases must proceed to the 4th and 5th steps in the evaluation process. These steps or hurdles involve the assessment of the claimant's residual functional capacity: the patient's ability to work. All of the patient's symptoms must be considered as to the their effects on the patient's functional capacities. Generally, "...the conclusion about whether...individuals [under age 50] are disabled will depend on the nature and extent of their functional limitations ."

The patient's residual functional capacity, according to the Ruling, should again be documented in his/her longitudinal clinical record. The patient and doctor should work, over time, to build this record --with an eye to both obtaining benefits and to future reviews.

As discussed above, Social Security emphasizes a detailed record for a 12 month period preceding the month of application (or a review.)

Treating and medical sources should include the following assessments in the longitudinal clinical record: "...extent and duration of an individual's impairment(s), including observations and opinions about how well the individual is able to function, the effects of any treatment...and how long the impairment(s) is expected to limit the individual's ability to function. Opinions from an individual's medical sources, especially treating sources, concerning the effects of CFS on the individual's ability to function in a sustained manner in performing work activities or performing activities of daily living are important...In this regard, any information a medical source is able to provide contrasting the individual's impairment(s) and functional capacities since the alleged onset of CFS with the individual's status prior to the onset of CFS will be helpful..."

**Letters Supporting Disability Claim:**

The Ruling requires that when an individual's statements "...about the intensity, persistence or functionally limiting effects of symptoms are not substantiated by objective medical evidence, the

adjudicator must consider all the evidence in the case record, including any statements by the individual and other persons concerning the patient's symptoms." [Statements]"...assessing an individual's ability to function on a day-to-day basis and to depict the individual's capacities over a period of time" should be obtained from: 1) neighbors, family, friends, clergy; 2) past employers, rehabilitation counselors, school teachers concerning the person's ability to function in the work place or the relevant facility; 3) other health care providers, e.g., nurse practitioners, physician assistants, naturopaths, chiropractors, therapists; 4) others with knowledge of the patient.

### **Examination by Social Security Doctors and Claims of Conflicting Evidence:**

Two other portions of the Ruling should be noted. First, the section on Consultative Examinations. If the adjudicator finds that the evidence submitted is inadequate to determine whether the individual is disabled, then the adjudicator must **first** recon tact the patient's physician(s) to find out if the additional information needed is readily available.

If not the agency will obtain a consultative examination from a medical source of its own choosing. Thus, it behooves patients to work with their physicians to submit comprehensive medical evidence and documentation of disability.

Second, when conflict develops between conflicting medical evidence in a patient's record, then Social Security is required to give deference to medical opinions from the patient's treating sources.

### **Conclusion:**

This Ruling will become the new basis for evaluating CFIDS disability claims and reviews. Anyone filing a claim or who is being reviewed should be familiar with it and, to the best of their ability, provide as much as possible of the evidence required by the Ruling.

Patients and their doctors will have to propose and press for the acceptance of other diagnostic medical signs and symptoms and laboratory tests as allowed by the Ruling.

### **Letters from your Primary Care Physician (continued):**

Now that you are familiar with how CFIDS is formally diagnosed, and how the new Ruling affects the Social Security evaluation of CFIDS, we turn again to the needed letters of documentation from your primary care physician.

It is not enough for your doctor in his/her letter simply to state that you have 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.

Dr. Anthony Komaroff, a leading specialist in CFS, cites the following laboratory abnormalities as supportive of a CFS diagnosis:

**Table 1**

**Laboratory Abnormalities and Chronic Viral Fatigue Syndrome (CFS)\***

Mild leukopenia (3000-5000/mm)  
Moderate monocytosis (7%-i 5%)  
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  
EBV antibodies:  
    Viral capsid antigen - IgG > 1:640  
    Viral capsid antigen - IgM - not detectable  
    Early antigen ~ 1:40  
    EB nuclear antigen < 1:5

*\* It is unusual for more than two or three of these findings to be present in any single patient.*

Also see Appendix II for a further list of diagnostic tests compiled by Dr. Charles Lapp. Any tests falling within the above ranges should be submitted by your doctor.

In most cases the physician would then document that the evaluation had found no illness or condition that would exclude a diagnosis of CFS and therefore would provide an alternative diagnosis. (If the individual clearly has CFS and there is the presence of an exclusionary condition, the doctor can still provide a CFS diagnosis, see above for discussion.) 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 onset, and 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 CFIDS symptom checklist (see Appendix II.) 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 evaluation phase (including those illnesses or conditions that fit the criteria that do not adequately explain chronic fatigue. These are the so-called inclusive diagnoses whose presence does not rule out a diagnosis of Chronic Fatigue Syndrome - see above discussion.) Such conditions may include Fibromyalgia, chemical sensitivity disorder, unresolved Lyme Disease, etc. The question often arises as to whether transient and non-serious secondary depression should be documented. Please see discussion in Appendix IV for a full discussion of this issue. Also in cases in which an individual clearly has CFS, but there is an exclusionary condition (example: A major depression which was fully resolved in the past), it would seem better for the patient to find a physician who can provide a diagnosis of CFS rather than receiving a diagnosis of idiopathic chronic fatigue since Social Security has no diagnostic

listing at this time for idiopathic chronic fatigue.

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 CFS symptoms - this should be noted if it is in fact the case.

The preceding discussion has focused on your physician's letter. 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 CFIDS. 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 during the course of treatment that 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 CFS [listed in the new Diagnostic Criteria, see Appendix I,] 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 II entitled, "*Helping Your Doctor Prepare Your Medical Report.*" This Appendix has Recommended Documentation of CFS Disability to be submitted to Social Security and/or for Private or Employer Disability.



Based on a number of disability lawyers' extensive experience adjudicating CFS cases, the Memo details the specific documentary evidence that should be submitted to Social Security (and other disability carriers). Following the Memo's suggestions should definitely strengthen a claimant's case.

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

Also included in the Appendix 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 II 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.

## **Supplementary Diagnostic Materials**

Letters by specialists supporting your diagnosis, including the results of specialized neurological, hematological, immunological, or neuropsychological testing should be submitted. Whether or not you are able to submit the documentation requested by the new Ruling, the supplementary testing results discussed here should strengthen your case.

Neuropsychological testing is achieving importance as a 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 CFS. See the appendix IV 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 CFIDS; 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 CFS, that your symptoms cannot be accounted for by an alternative diagnosis of primary depression*. (Neuropsychological testing can help differentiate CFS from a diagnosis of primary depression.)

Once a firm diagnosis of CFS is established, the doctor may document any diagnosis of secondary depression caused by the patient's struggle with the effects of CFS. It is very important that the doctor,

when discussing depression, distinguish between primary depression (which would cause your symptoms) and secondary depression (which would be a result of your symptoms). *See the appendix 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 in section B of Appendix IV as well as appendix VII 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 describe 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 CFS diagnosis and which increase your overall level of disability.

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

In the second part of your primary physician's letter, your doctor must document in some detail how your illness prevents you from performing even light, sedentary, part-time work on any continuing basis.

The doctor 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 Ruling for guidelines on how you and your doctor(s) should document your inability to work and perform daily tasks. (Please see above the section "Documenting the PWC's inability to Work" in the summary of the Ruling.) Use the rest of the information in this section (and Appendix II) as a supplement, when applicable, to the guidelines set forth in the Ruling. These guidelines (the Ruling's guidelines first) 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 your doctor(s) should document in the report, so make sure you give a copy of these guidelines to your doctor(s).

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, 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.

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. (copy in Appendix II.)

### **Cognitive Dysfunction: Its Limiting Effects on a PWC's Ability to Work**

Neurological impairments and cognitive dysfunction impairments of thinking, memory, concentration, etc., seriously affect many CFS patients. These impairments can profoundly limit a person with CFIDS' (PWC) 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 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 routinely relied upon. 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.)

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 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 CFIDS symptom checklist (see Appendix II) 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 - several diary-like formats are available for documenting the effects of your illness. (See the resources appendix.) 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 the third memo, Appendix III.

## **VI. Contacting Your Congressman about your Social Security Application**

You may wish to inform your congressman 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 congressman 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. The decision on your case will not be influenced in any way by the fact that you contacted your congressman; however, there may be fewer delays in your obtaining a decision since Social Security will be aware of your Congressman's interest. It is not at all necessary for you to contact your congressman 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

### Obtaining a CFS and/or Fibromyalgia Diagnosis

Obtaining a well-documented 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.

In the case of CFS, this is especially true. Currently, in the United States, the method of diagnosis recognized by the medical community and the Social Security Administration is the 1994 Centers for Disease Control Diagnostic Criteria published in the December 15, 1994 issue of the *Annals of Internal Medicine*.

The issues of the application of the CFS diagnostic criteria to obtaining Social Security or other forms of disability are discussed extensively in the earlier portion of this booklet. However, because of the difficulty patients sometimes have in obtaining a diagnosis from their physicians, it is sometimes useful for a patient to be able to give his/her doctor a copy of the actual scientific Journal article containing the diagnostic criteria. Once a physician knows from an authoritative source how to make the diagnosis, a well-documented diagnosis may be easier to obtain.

Because of space limitations, we are unable to provide a full copy of the *Annals of Internal Medicine* article in this booklet. However, because of its potential usefulness to patients, the article is available for downloading from this website. For those obtaining a paper copy of this booklet, a copy of the Journal article is available on request.

There is no doubt the 1994 Criteria was poorly drawn in terms of carefully defining CFIDS. It is a research definition, and is not meant to be applied rigidly to clinical diagnoses. Before giving the definition to an uninformed doctor, please read the earlier discussion in this booklet carefully, and if necessary, give a copy of the discussion to your physician.

In 2003, a much better CFIDS case definition 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 definition and will probably be used by some doctors to make clinical diagnoses.

However, the 1994 definition is the only one, so far, recognized by Social Security and Insurance companies, so applicants will have to have their illness validated under this definition.

Also included in this Appendix, below, is a short explanation of fibromyalgia, as well as the **official fibromyalgia case definition**.

“What is Fibromyalgia” (from the Mass. CFIDS/ME & 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. It is a chronic pain syndrome often associated with CFIDS, and sometimes confused with it. The pain can be

severe enough to interfere with routine daily activities. It 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.

## **Fibromyalgia Case Definition**

**How is FM Diagnosed?** The 1990 American College of Rheumatologists diagnostic criteria are:

1. Widespread pain for at least 3 months.
2. Pain in all four quadrants of the body: right side, left side, above and below the waist.
3. Pain in at least 11 of 18 specified tender points when they are pressed. These 18 sites cluster around the neck, shoulder, chest, hip, knee, and elbow regions.

## APPENDIX II

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

This Appendix includes the following:

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

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

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

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

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

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

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

B. Excerpts from the Social Security Administration Fact Sheet (publication #64-063): "Providing Medical Evidence to the Social Security Administration for Individuals with Chronic Fatigue Syndrome - A Guide for Professionals" (1996).



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

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

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

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

### **Memo from A Disability Lawyer's Perspective: Recommended Documentation of CFS Disability Claim to be Submitted to Social Security and/or for Private/Employer Disability**

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

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

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

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

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

3. Detailed narrative reports by primary CFIDS care physician and all other health care providers which include:

(a) The medical history.

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

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

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

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

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

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

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

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

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

(g) Prognosis, which for CFIDS, is at present, uncertain and guarded.

(h) The medical opinion, if truthful and correct, to the effect that the patient has been totally and permanently disabled by reason of the unpredictability of the frequency and severity of his/her multiple physical symptoms since the date of onset, and for not less than twelve consecutive months; and in any event, for the foreseeable future in that at present, there is no known treatment, cure or management program for this disease. The Claimant is unable to engage in, and more importantly, sustain, any gainful employment activity, even light part-time, sedentary work from home.

(If the language in this item truthfully applies to the claimant, it is suggested that the **physician**

**directly incorporate the language into his/her Report.)**

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

## **Checklist of CFIDS Symptoms**

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

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

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

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

### **2. Psychological symptoms**

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

- Psychosis (1%)

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

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

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

Pharyngitis (50- 75%) (inflammation and discomfort of the pharynx)

Dyspnea on exertion (labored breathing or hunger for air)

Worsening of premenstrual symptoms (70% of women)

Tachycardia (40-50%) (abnormal; rapid heart action)

Chest pain  
Nausea (50-60%)  
Parathesias (30-50%) (abnormal sensation of tingling or discomfort at odd intervals)  
Diarrhea, intestinal gas or irritable bowel (50%)  
Dry eyes (30-40%)  
Dry mouth (30-40%)  
Anorexia (30-40%)  
Hair loss  
Cough (30-40%)  
Finger swelling (30-40%)  
Cold hands and feet  
Rash (30-40%)  
Herpes simplex or shingles (20%)  
Frequent canker sores

**5. Less Common Symptoms:**

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

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

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

1. Low blood pressure
2. Tender/palpable lymph glands
3. Allodynia (sore or tender skin)

4. Tender trigger points
5. One pupil larger than the other
6. Coated tongue (candida) and other skin conditions
7. Rosatia (skin condition where blood vessels grow close to skin a/k/a butterfly rash)
8. Acne-resistant to usual treatment
9. Lesions on the body (red & crust - come and go)
10. Shingles
11. Atrophy of fingers ("furrows" which can obscure a fingerprint)
12. Swelling of the lymphatic system, especially in the nodes along clavicle, frequently left side clavicle
13. Thoracic duct tender
14. Check for clonus
15. Signs of Romberg
16. Crimson crescents to the sides of uvula
17. Check for low-grade fever
18. Brain scan

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

## **I. Excerpts from CFS Social Security Documents**

These excerpts when not in conflict with the new Social Security Ruling may be useful in elaborating the Ruling – especially when applicants must use medical signs, symptoms and lab tests not specifically listed in the new Ruling.

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

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

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

### **How Social Security Determines Whether a Person is Disabled**

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

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

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

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

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

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

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

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

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

## **Medical Evidence**

**Longitudinal medical records (i.e., records describing the illness over time) are very important for disability claims evaluation under Social Security and are especially significant in assessing the presence and severity of CFS. Every effort should be made to provide as much detailed longitudinal information as possible, either with photocopies of examination and treatment records or in a narrative report (or both).**

Ideally, a medical report should include the following elements:

- Medical history;

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

## **Medical History**

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

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

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

- sore throat,
- tender cervical or axillary lymph nodes,
- muscle pain,
- multi-joint pain without swelling or inflammation,
- generalized headaches of new origin,
- unrefreshing sleep,
- post-exertional malaise,
- impaired memory or concentration,
- chronic intermittent fever,
- muscle wasting,



- neurological deficits,
- difficulties with vision, and
- other mental abnormalities.

### **Laboratory Test Reports:**

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

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

### **Laboratory Findings:**

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

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

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

The results of tilt-table testing to evaluate neurally-mediated hypotension may also be included;

these results may be abnormal in persons with CFS.

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

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

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

### **A Guide for Health Professionals**

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

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

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

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

...Although you may reach a diagnosis of CFS on the basis of your patient's symptomatology (after ruling out other factors), the Social Security law requires that a disabling impairment be documented by medically-acceptable clinical and laboratory findings. Statements merely

recounting the symptoms of the applicant or providing only a diagnosis will not establish a medical impairment for the purposes of Social Security benefits. We must have reports documenting your objective clinical and laboratory findings. Thus, it is essential that you submit all objective findings available concerning your patient's condition, even if they relate to another disorder or establish that the person has a different condition.

SSA Pub. 64-063

ICN 953800

## **Incapacity Checklist**

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

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

*How does your condition affect:*

your daily activities

your ability to stand, sit, or walk for a long period

your ability to lift or carry weight

your ability to understand, carry out, and remember instructions

your ability to respond appropriately to your supervisor and co-workers

other physical or psychological functional restrictions, and

your ability to adjust to the stress of a work environment

## **Sample Doctors' Letters**

This section includes a selection of sample doctor's letters that were actually written to Social Security to document patients' CFS disability claims. These letters are provided to help show how a doctor's letter should be written and the type of information it should contain in order to make the letter strong and effective.

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

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

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

## **Explanation to Letter #1**

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

Letter # 1 is a good example of the type of letter that would be effective in establishing a CFS patient's eligibility for Social Security disability. It adequately documents the patient's CFS diagnosis by providing the necessary detailed review of symptoms and symptom history. The letter also states that the patient's depression is a *result* of the CFS rather than the *cause* of the CFS symptoms. The letter also provides the required assessment of the patient's inability to work and to perform various tasks and activities. The doctor's statement that the patient is 100% disabled and unable to work is especially strong. While this letter represents a good medical report, an even stronger report would provide more detail on the patient's inability to perform a variety of daily tasks; the letter should also include an evaluation of the patient's capacity for lifting, walking, sitting, and standing.

The letter would also be stronger if it included the results of diagnostically relevant laboratory tests. With these suggested additions, Letter # 1 would be an excellent medical report.

## **Letter #1**

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

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

---

Secondary depression that is a result of her long-term illness is also worrisome. (\_\_\_\_\_) is currently taking amitriptyline as a joint therapy for that as well as for her sleep disorder and myalgias.

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

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

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

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

Sincerely,

(\_\_\_\_\_ MD)

## **Explanation to Letter #2**

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

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

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

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

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

questionnaire isn't strong enough, then you can ask your doctor to consider revising it based on your suggestions.

## **Letter #2**

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

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

## **Explanation to Letter #3**

Letter #3 is included for several important reasons. First, the letter documents a case of fibromyalgia disability and, therefore, should be helpful to those patients with fibromyalgia reading this booklet. This is an excellent sample medical report (except for the limitations described below) for showing how to document disabling cases of both fibromyalgia and chronic fatigue syndrome. The first paragraph of the letter documents a physician's diagnosis of the patient's disabling fibromyalgia. The physician's method of documenting the diagnosis is adequate but somewhat weak. Instead of directly detailing the patient's symptoms, the physician makes reference to the symptoms typical of fibromyalgia and then goes on to state that the patient's individual symptoms are in line with fibromyalgia symptomatology. Hence, the diagnosis is by extension from the general illness with little reference to either the severity or intensity of the individual's actual symptoms. The letter would definitely be strengthened by more documentation of the individual's actual symptoms, including the intensity, severity, and chronicity of the symptoms. The letter would also be strengthened by the inclusion of a summary history of the development of the illness and its severity.

A major reason for the inclusion of this letter is its listing of the patient's inability to perform specific daily activities. The extent of the patient's profound disability is completely and unmistakably documented by the extensive and almost overwhelming amount of detail, which, in its entirety, shows how disabled the patient actually is. With this type and amount of detail of the patient's limitations in performing specific daily activities, it's hard to imagine that Social Security would not understand that the patient is completely and totally disabled. Certainly, many doctors would not be expected to provide the amount of detail regarding the patient's specific limitations that is provided in this letter. However, a letter which provided only half the details contained in this sample letter would constitute convincing documentation of the patient's disability. Additionally, one would reasonably assume that the patient provided the physician with the extensive list of her daily limitations. Disability applicants can assist their physicians with preparing medical reports by providing them with this type, if not quite so lengthy, listing of their inability to perform actual daily activities. Such a listing should fully and

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

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

### **Letter #3**

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

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

Dear Sir:

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

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

Ms. ( ) has had marked impairment of her daily activities and finds it difficult to get out of bed, to dress herself, to get out of a bathtub, to wash her back and hair, to dry herself, to cut fingernails and toenails. to apply makeup, to walk up or down stairs, to get up and down a curve. She finds it impossible to walk up or down a slope. She has difficulty in cutting meat, opening bottles, pouring a cup of tea or coffee, opening jars, reaching above or below the counter-top, filling saucepans, carrying pans to the stove, removing hot dishes from the oven, draining vegetables, pouring hot water from kettles. She finds it impossible to peel or slice vegetables, grocery shop without assistance. She has difficulty in carrying a full cup and saucer or hot casserole. She has difficulty with scraping and stacking dishes, washing dishes, picking up objects from the floor, wiping up spills on the floor, sweeping the floor, using a dustpan, cleaning the refrigerator. She finds it impossible to scrub pots and pans, mop the floor, wash the floor or clean the oven. She has difficulty in hand-washing laundry or machine washing, laundering and folding sheets, as well as making beds, changing beds, using scissors, handling coins. She finds it impossible to wring laundry, hang laundry on the line, iron, dust, or clean high and low surfaces, vacuum: clean out the bathtub. She has difficulty in getting in and out of a car and finds it impossible to get onto a bus or stand on the bus holding the overhead bar, or descend from a bus. She has difficulty in managing medicine bottles, holding a book, turning pages, winding a clock or watch, sweeping the porch, opening and closing windows, opening milk cartons, managing wall plugs, using a spray can, opening doors with keys. She is unable to write for fifteen minutes, shuffle and hold a hand of cards, care for her garden.

While an exercise program has been recommended and has been attempted, some individuals such as Ms. ( ) experience intolerable pain even with minimal conditioning exercises; however, she

has been encouraged to attempt to slowly increase her activities as permitted, but with little success. To date, I believe that her disorder is at a plateau.

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

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

Sincerely yours,

M.D.

## **Helping Your Doctor Prepare the Medical Report**

By giving your doctor the latest Social Security Memos in this Appendix, the Memo, the Incapacity Checklist, and perhaps Letters # 1, #2, and/or #3 (but only if you explain that each of these letters requires additional information), you will be helping your doctor prepare a strong letter on your behalf.

The Mass Disability Law Center in its booklet, *"How to Secure and Protect your Social Security Disability Benefits,"* suggests that patients should, if possible, ask their doctors and other providers to send them (the patients) copies of all the reports and documents to be submitted to Social Security. The patient him/herself would then submit the documents to Social Security -- after making copies of the documents for his or her own records. The patient, in this procedure, takes the responsibility for collecting and submitting some records to Social Security.

*There are two advantages to such a procedure:*

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

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

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

The big drawback to the above procedure is that often the CFS patient is too sick and exhausted to do



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

*Note:* A good alternative to the above procedure is simply to ask your doctors to send you copies of all records that they send to Social Security. This way, you will at least know what has been sent and you will have copies for your own records.

## APPENDIX III

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

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

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

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

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

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

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

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

2. It is also recommended that at the time the patient applies for the hearing, he/she begin to prepare the following exhibits, to be submitted to the judge approximately one month prior to the hearing date. In preparing these exhibits, as well as the pertinent hearing forms, the patient should collaborate in their preparation with a friend who also would be the person driving the patient to and from the

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

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

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

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

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

- a) Fill out the *CFIDS Symptom Checklist*. Please complete, date and sign the list after checking symptoms. In filling out the form, you should include all important recurring symptoms produced by your illness. Generally these will be symptoms that have lasted or recurred throughout your illness. (see Appendix II for checklist)
- b) *Claimant's Medications* -- complete, date and sign.
- c) *Typical day in the life of (name)* from 8:00 A.M. one day to 7:59 A.M. the next day, in outline form on an hour-to- hour basis.
- d) *Examples of episodes which highlight my cognitive dysfunction*. List some of the major examples of cognitive dysfunction which do not involve operation of a motor vehicle -- approximately 7-10 examples will be sufficient, also signed under the pains and penalties of perjury at the end.
- e) *Why I am unable to do light part-time sedentary work from my home*. List the reasons why you are unable to perform:  
  
Word-processing and typing from your home;  
telemarketing from your home;  
stuffing envelopes;  
companion to the elderly;  
and child care from own home. Again, at the end, sign under the pains and penalties of perjury and date.
- f) *List of activities formerly enjoyed*:. Prepare a list of activities formerly enjoyed by you, which you are no longer able to do by reason of your total and permanent disability from CFIDS. Likewise at the end, please sign under the pains and penalties of perjury and date.

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

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

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

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

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

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

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

5. The attorney should screen all reports, medical and otherwise, before such reports are forwarded (by the attorney) to Social Security or the ALJ. By so doing, any matter or language requiring clarification or correction can be discussed by the attorney with the provider. (Necessary changes in letters can be made before the letter is submitted.) Normally, if possible, the doctor will provide the claimant with the report, which the claimant will then give to the attorney. (This process also allows the attorney and client to cross-check necessary information.)
6. Prior to the hearing a vocational expert who has an understanding of CFS could test the claimant to determine his or her level of ability and stamina. As part of the testing process, the expert should arrange for the claimant to call several days after the conclusion of the testing to report the after-effects on the claimant's health resulting from the testing process. Often, following the rigors of testing, the claimant will be bedridden for several days. If this occurs, a notation to this effect in the vocational

report is very useful.

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

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

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

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

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

## **Further Suggestions**

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

1. Maximize the relationship between the severity of the symptomatology and how it renders the claimant totally disabled.

2. Whenever a claimant appears before an Administrative Law Judge, it is a good idea to have them driven there by a friend or family member - this helps reinforce the dependency upon others for such matters as grocery shopping, routine short-term travel, and most important of all, the key buzzword - "unpredictability" of onset of symptoms - if the Judge asks, "How did you get here today?"

3. In their appearance before the Administrative Law Judge, it is advisable for the claimant to have prepared in advance a *list* of their most frequent daily symptoms, how each symptom disables them, the usual extent to which it disables them, and most important, how any one or more of the symptoms can come upon them with little, if any, advance notice (resulting in the unpredictability factor, which renders claimants unable to maintain any viable work schedule, with any degree of regularity).

4. From a list prepared in advance, it is recommended the claimant give a brief synopsis of a "typical day in the life of the claimant." The use and need for notes to do this helps emphasize the short-term memory loss and cognitive dysfunctions from which claimants suffer.
5. It is preferred that if possible they keep their emotions partially, but not entirely, in check, to the extent they are able. If they are answering a question which to them is an emotional trigger, claimant should try to retain composure even if it takes an extra moment or so -- take a deep breath and relax -- and counsel should temporarily, if able, switch claimant onto a less emotional area of his/her disability, to help them regain composure and then field the question in a short while. This effort is usually appreciated and respected by the Administrative Law Judge.
6. Claimants should dress casually and comfortably wearing the same type of clothing they would wear around the house if, by way of example, guests were coming to visit them a few days after they have returned home from the hospital after a minor surgical procedure -- loose pullovers, sweat pants, sneakers, etc., are fine as long as neat and clean. Claimant can even explain why generally they wear this style of attire -- because of the reduced effort it takes to dress themselves on those days when they are able to get up and out of bed.
7. The key to any of the reports is to have an evaluating physician review all past reports, tests, and records, and detail briefly for the patient what symptoms cause them the most difficulty and how the unpredictable nature of the severity and frequency of the symptoms does render them unable to engage in any light, adjusted or sedentary work, never being able to reliably appear for work most days either punctually or at all.
8. When filling out a Request For Consideration form, it is highly recommended that the claimant indicate that he will be producing new and additional evidence and that (if truthful) his symptoms have, become more severe and more frequent, i.e., to show a condition which is a progressive disabling condition.
9. An Administrative Law Judge might ask a claimant if he could walk two blocks -- and the answer may be truthfully yes -BUT it is up to the claimant to add that if he does, he will end up being bedridden for the next 4 days (as an example). Many CFS patients can perform lengthy tests conducted in offices of psychologists, physicians, vocational counselors, and physical therapists and, of course, the reports of these professionals to Social Security would be that the tests were performed by the claimant successfully. Then it becomes up to the claimant and his representative to indicate to the Administrative Law Judge the after-effects of these physically and possibly emotionally strenuous tests.
10. De-emphasize the depression aspects of the illness in that that could be a stigma. Once made part of the record, it is very difficult to overcome, unless of course we are referring to a secondary depression resulting from the experience of having to undergo such a major change in lifestyle and ability.
11. A special effort should be made not to overwhelm either his/her representative or the Administrative Law Judge with a plethora of material or a day-to-day diary for the past two or more years. First, anyone capable of writing and producing so much material could probably get light work proofreading or writing short stories at home -- or at least it would appear that way to a vocational expert or Administrative Law Judge. Second, neither the claimant's representative nor the

Administrative Law Judge needs to know everything that might be contained in a plethora of material that could qualify as an autobiography. A competent representative can advise a claimant as to what information is being sought by the Administrative Law Judge by which he can render a favorable ruling expeditiously if he so finds. Too much material will only confuse and cloud the really few key issues that the Administrative Law Judge must have addressed in order to render a fair and hopefully favorable decision.

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

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

## **APPENDIX IV**

### **The Use of a Diagnosis of Depression or Other Mental Impairments in a CFIDS 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 represented by many 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 is that the use of these diagnoses should be avoided, if possible.

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

**The new Social Security CFS Ruling injects new information and challenges some of the key assumptions in the discussions that follow.** Briefly, the new Ruling lists a limited number of specific medical signs, laboratory findings, and cognitive and mental findings which constitute a finding of CFS. Because the new Ruling provides a relatively short list of specific qualifying signs and tests, CFS evaluation may turn out to be a less flexible process. Hence each listed finding and lab test that an applicant can qualify for may become more singularly important. Thus, under cognitive and mental findings, a finding of secondary depression may be more important in qualifying for disability than before the Ruling

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 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 would be well-advised to think carefully before rejecting the use of secondary depression as a means of establishing a CFS claim.



## **A. The "Legal Services" Position: The Positive Use of Secondary Depression and Mental Impairment in a 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 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 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 CFS diagnosis) may well negate a diagnosis of CFS, and therefore cause a CFS disability claim to be rejected (since primary depression often looks somewhat like CFIDS).

However, 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.**

The community of legal assistance disability attorneys in Massachusetts *believes in the use of mental impairment diagnoses (when such diagnoses are well-documented) as a necessary aid in gaining the acceptance of disability claims.*

Legal assistance attorneys generally recommend 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. The legal assistance community believes that looking at the whole person - physically and psychologically - is a proper and valid way of proving disability.

## **Problems Which May Develop Between CFS Patients and Their Attorneys Regarding Documentation or Submission of Mental Impairment Diagnoses**

Problems, however, have occurred with the use of psychological testing by some legal assistance 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 legal aid 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 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 a CFS patient, such false diagnoses may consist of
  - a) an erroneous psychiatric diagnosis as a substitute for the real CFS diagnosis, or
  - b) an additional, false psychiatric diagnosis.

**A psychological report which falsely substitutes a mental impairment diagnosis for a 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.

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).

Any claimant who wishes to maintain control over his or her attorney's submissions to Social Security is advised, during the first or second interview with the attorney, to obtain a definite and specific promise that he or she will be permitted to review all materials before submission and will, additionally, have the right to veto any proposed submission.

As stated above, the use of psychiatric documentation of a secondary depression may actually help clarify a 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 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.

## **Issues of Cognitive Dysfunction and Neuropsychological Testing**

**Cognitive dysfunction** (memory loss, difficulty thinking, etc.) frequently affects CFS patients. It is thought to result from the organic and neurological aspects of 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 CFIDS**. The patient must ask the tester beforehand if he/she is familiar with CFIDS, and if the tester can do the interpretation in a way that takes the illness into account. Sometimes, testers unfamiliar with CFIDS can misinterpret the tests to the detriment of the CFIDS 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 routinely 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 CFIDS Disability Application**

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 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 CFS and primary depressive illness have a number of common symptoms (but 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 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 some disability lawyers, 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 (i.e. the individual could not work, given the level of depression). 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 2003, some insurance companies are issuing new policies for “subjective” illnesses such as 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.

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 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. Many disability lawyers believe that, in most cases of CFS, use of the mental impairment or depressive diagnosis is not required to obtain a favorable disability finding. 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. Try to avoid the introduction of these diagnoses, since 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.

10. In recent years, many disability lawyers have found that administrative law judges are more aware of the severely disabling effects of CFS, and are generally not unsympathetic to claimants' applications: however, they do need the detailed medical evidence of physical incapacity linked to the inability for gainful activity.

## APPENDIX V

### **Landmark Federal Court Decision Establishes Right of Persons Diagnosed with and Disabled by CFIDS 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 CFIDS 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 CFIDS patients. The decision will have the effect of requiring the Social Security Administration to more clearly recognize CFIDS 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 CFIDS disability claims before Administrative Law Judges (ALJ), and when necessary, before the federal courts.

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

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. *Mongrelize v. Baxter Trevino* Long Term Disability Benefit Plan, 1995 WL 34268 (9th Cir. (Cal.)) Important decision upholding CFIDS claim against employer disability carrier; carrier claimed that the person with CFIDS 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 VI

### 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 1999 Social Security Ruling on 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 Person with CFIDS (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 PWC’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 PWC’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 at 617-522-5835. 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(as). 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(as). 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 Appendix II.

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 obtains 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.

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 III 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 VII

### 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 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 CFIDS 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 CFIDS is obtained so that there is no question of the validity of the CFIDS 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 CFIDS, 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 CFIDS, that such depression would not exist without the CFIDS, 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. CFIDS Disability Committee* at (617) 522-5835 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. *The Mass. CFIDSME & FM Disability Committee*, (617) 522-5835, has written a short fact sheet on *Disability Retirement benefits*. Call the Committee if you would like a copy.

## **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."

Reproduced from *Working While Disabled - A Guide to Plans for Achieving Self-Support While Receiving Supplemental Income* published by the Social Security Administration.



## **OTHER DISABILITY RESOURCES**

Disability Packet (59 pages) Includes *Chronicle* articles about disability benefits and helpful advice for persons with CFIDS trying to obtain Social Security Disability Insurance Benefits. #6030 \$8.00. Mail request to the CFIDS Association of America, P.O. Box 220398, Charlotte, NC 28222-0398. Credit card orders may be placed by phone (704-365-2343).