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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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
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**

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

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**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.

<table>
<thead>
<tr>
<th>Property</th>
<th>Maximum Value</th>
<th>Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Savings accounts and other assets (excl. items below)</td>
<td>$2,000</td>
<td>For a single person. For a married couple.</td>
</tr>
<tr>
<td></td>
<td>$3,000</td>
<td></td>
</tr>
<tr>
<td>Car</td>
<td>-</td>
<td>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.</td>
</tr>
<tr>
<td>House</td>
<td>-</td>
<td>Unlimited, as long as you live in it.</td>
</tr>
<tr>
<td>Furniture and other household or personal property</td>
<td>-</td>
<td>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.)</td>
</tr>
<tr>
<td>Life Insurance</td>
<td>-</td>
<td>Life insurance is considered an asset. Term insurance is not taken into account.</td>
</tr>
<tr>
<td>Burial insurance</td>
<td>$1,500</td>
<td>The policy has to specify the proceeds can only be to pay burial expenses of the insured individual.</td>
</tr>
</tbody>
</table>

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 then 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.)