# HOW TO APPLY FOR SOCIAL SECURITY DISABILITYBENEFITS IF YOU HAVE MYALGIC ENCEPHALOMYELITIS/ CHRONIC FATIGUE SYNDROME (ME/CFS)

With Additional Information on Applying for Benefits If You Have Fibromyalgia

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## **DISCLAIMER**

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

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

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#### HOW TO USE THIS BOOK

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

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

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

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

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

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

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

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

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

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

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

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

Also, on our website we have an entire disability section with many important articles relating to many different aspects of needed assistance for those who lose employment because of the illnesses. The disability home page is at <a href="https://www.massmecfs.org/disability">https://www.massmecfs.org/disability</a>

Also, there is a specific section on Social Security disability with articles and information that are an important supplement to this Booklet. Applicants should check this section out at <a href="https://www.massmecfs.org/social-security-disability">https://www.massmecfs.org/social-security-disability</a>

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

Ken Casanova

# **INTRODUCTION**

# Eligibility for Social Security Disability Programs

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

# The two programs are:

SSDI - Social Security Disability Insurance SSI - Supplemental Security Income

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

# Disability Eligibility Standards for SSDI and SSI

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

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

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

#### Financial Eligibility Standards for SSDI

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

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

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

The necessary period of time worked is measured in "quarters" (three months). During each year you worked, depending on the amount of money you earned, you can accumulate up to 4 quarters.

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

You qualify for SSDI if you have accumulated the required number of quarters in a specified number of years <u>immediately prior to your date of disability</u>. 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.)

<b>Quarters</b>	Needed	to (	Jualify	for	the	SSDI	Program
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Age	Quarters	Within
16-24	6	3 years
24	8	4 years
25	10	5 years
26	12	6 years
27	14	7 years
28	16	8 years
29	18	9 years
30	20	10 years
31-65	20	10 years

# (Reprinted with permission of the Disability Law Center)

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

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

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

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

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

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

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

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

## **Supplemental Security Income (SSI)**

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

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

# Financial Eligibility Standards for SSI

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

Maximum Property Value That a Disabled Person Can Own and Still Be Eligible for the SSI Program						
Property	Maximum Value	Conditions				
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 that the proceeds can only be used to pay burial expenses of the insured individual.				

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

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

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

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

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

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

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

## & Children Program (EAEDC)

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

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

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

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

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

## Food Stamps and Fuel Assistance:

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

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

For both programs you can also use your search engine.