

**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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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 may not apply elsewhere and visa-versa. Moreover, what is valid today in this booklet when it goes to press may not be valid after it is published. The Massachusetts 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

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).