

**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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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 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

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.

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.