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 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
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.