

What if I have no long-term disability insurance of my own or through an employer?

Very often a disabled individual is working at a job without Long-Term Disability (LTD) benefits, or has been out of work and is no longer covered by an LTD policy. Under these circumstances, what benefits are available for financial assistance, medical insurance, and other needed help?

The primary alternative to long-term disability insurance for financial and medical insurance is *Social Security Disability Benefits*

These benefits are provided through the Federal Social Security Administration.

The Massachusetts CFIDS/ME & FM Association has written a comprehensive booklet

[MassCFIDS/ME & FM Disability Handbook:](#)

[How to Obtain Social Security Benefits if You Have Chronic Fatigue Syndrome \(CFS/CFIDS\)](#)

The content in the booklet also generally applies if you have fibromyalgia (FM), or even multiple chemical sensitivities (MCS). This portion of the web section will outline some major elements of the Social Security program, but the book will provide you with the needed comprehensive information

What are Social Security Disability Benefits?

Social Security provides two financial assistance programs to people who are disabled.

The term "disabled" under Social Security regulations means that: a person is unable to do any work, even part-time, sedentary work on a *predictable* basis, and this condition has lasted or is expected to last at least a year. This definition is termed "permanently and totally disabled".

Under this definition a person is unable to perform any "substantial, gainful activity." (This is a more encompassing standard than many long-term disability policies, which may allow for some level of work.)

The key phrase for many disabled patients is being able to do any work on a "predictable basis". For example, especially in the case of the Chronic Fatigue Syndrome/Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFS/CFIDS/ME) or fibromyalgia

(FM), a person might be able to work 4 hours today on a computer, and 4 hours tomorrow on the phone, but then be unable to work for 3 days due to a relapse. This person would be considered disabled by Social Security. However, if a person could work 5 hours a day, 3 or 4 days a week on an ongoing, predictable schedule week after week, month after month—then the person would not be considered disabled.

To apply for Social Security Disability benefits, you simply call your Social Security office and state that you are disabled and need to apply. You should ask that an application be sent to you in the mail and should also request a date for a telephone interview. You should fill out the application prior to the telephone interview, so that your answers will be well-considered and clear. One date of importance is the date you became disabled—that is you stopped being able "to do any work, even part-time sedentary work, on a predictable basis." You may have been out of work for some period of time. Give the earliest date you fit this definition. You will also be asked when you first became ill. Give the date as requested—this may have been many months or years before you became disabled.

When you are interviewed for your application, make sure you communicate just how ill and disabled you normally are. If you have been having a few good days, you may be feeling hopeful and therefore tend to understate the severity of your illness. Most people want to be working and are ambivalent about being "disabled." As a result, they will express themselves to Social Security as if they are less ill than they actually are. Moreover, some patients go into a job interview mode and "put their best face forward." If you do not communicate to Social Security just how severely and chronically ill you are, then Social Security cannot know—and therefore has no good reason to grant benefits. If truthful, patients should think first of when they are having a bad day or a bad week in order to balance their presentation.

Social Security may have an application online. If possible it's best to fill out paperwork off-line, since then you can take time to consider and answer questions. A formal telephone interview is best, but if you are asked to be interviewed in person, then you must do so, unless you can persuade Social Security otherwise.

There are two Social Security Disability Programs—Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)

Both Social Security programs have the same standard of disability outlined above.

However, they differ in their financial eligibility standards and the amount of assistance they each provide.

Social Security Disability Insurance

A person qualifies for SSDI if they have worked and paid Social Security payroll taxes for a sufficient period of time prior to becoming disabled. Generally, if a person is over 30 they would have had to have worked 20 quarters (5 years, not necessarily consecutive) over the 10 year period prior to becoming disabled. You should check with your Social Security office to see if you have the necessary number of quarters. If you are lacking one or two quarters, check with the Massachusetts CFIDS/ME & FM Association; sometimes there is a way to achieve the necessary number. Our Social Security booklet will give you a full explanation of this category of eligibility.

There are no income or asset requirements for SSDI. You could be getting investment income or other forms of income for which you do not work. Also you can have assets of any amount.

The monthly disability payment will depend on how much average earnings or salary you had when you worked. If you worked part-time you will receive less. The amount may range from a few hundred dollars to over \$2000 a month. The average amount is about \$1,000-\$1200 per month for an average yearly earnings of \$20,000-\$25,000. Check with your Social Security Office to obtain an estimate of your monthly cash benefits.

Because Social Security Disability payments are often not enough to pay for all living costs, especially housing costs, many disabled persons find it necessary to apply for other forms of assistance, especially housing assistance, if they have no other source of income. These other forms of assistance are discussed in the sections [Other Needs](#) and [Disability Resources](#). Besides a financial payment, SSDI also provides Medicare medical insurance but there is a waiting period of 2 years from the date of disability. The Social Security medical insurance programs will be discussed in [Medical Insurance](#).

Supplemental Security Income

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" to qualify for SSDI. For people who do not have the required 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 can have—that is income from all sources. The income amount is the amount of SSI monthly payment, which varies by state. In Massachusetts the amount is somewhere in the area of \$600-\$700. (Check with your local Social Security office for the exact figure.) If you have income from any source(s) above this amount you will not be eligible. This includes income from a spouse. And any income you receive from SSI will be deducted from the little other income that you have. However, if you do qualify for SSI, you will get Medicaid, a comprehensive medical insurance plan, immediately. (See [Medical Insurance](#) for some details). You also will probably be eligible for food stamps and fuel assistance. Also there is an asset limit for SSI. You cannot have assets of more than \$2,000. You may have a car and a house that you live in. Call Social Security for more details. If your SSDI amount of monthly income is under the SSI payment limit, you will be able to collect from both programs. SSI will supplement your SSDI up to the SSI limit. You apply for SSI in the same way as SSDI.

Importance of Medical Documentation of your Disability

The key to obtaining either SSDI or SSI is the full medical documentation of your disability by one or more MD physicians. Your doctor must be willing to support your claim and provide the necessary medical reports, physician's office notes, medical records, etc.

The Process of Application

Applying for Social Security Disability can be a daunting and sometimes an extended process. Our Social Security Disability booklet [Mass CFIDS/ME & FM Disability Handbook: *How to Obtain Social Security Benefits if You Have Chronic Fatigue Syndrome \(CFS/CFIDS\)*](#)

) will arm you with the knowledge and persistence to navigate the process. There are normally 3 stages before a claim is approved, although sometimes a person can be approved at stage one or two. The better and more complete your medical documentation, the higher the chances are for a quicker approval. But you should not give up if you are disapproved at stage 1 or 2. Ninety percent of people who are approved are approved at stage 3. Most people with CFS/CFIDS/ME or FM who are truly disabled are accepted, although there is variation depending on the region of the country you live in.

The Waiting Period

The typical waiting period for Social Security approval of an individual's claim may take many months. If a person has little or no savings or assets, he or she may not have sufficient funds to meet their living expenses. Some people may have family or friends from whom to seek help.

There are some assistance programs that may help to bridge the waiting period "gap". (There is a six month waiting period from the date of disability before one's funds begin to accumulate. Once an application is approved, there is usually a check for retroactive accumulated funds. However, Social Security has a limit on retroactive funds paid to an older disability date. But there is no waiting period before you apply—you should apply as soon as you are no longer able to work.)

Working while applying for Social Security Disability

Many people who have no other income or resources ask, "How can I meet my expenses while I wait for Social Security? Can't I work just a few hours a week?" In general, any work during the application period is viewed suspiciously by Social Security as possible "substantial gainful activity". (This phrase means you are not disabled.) The best advice is not to work at all while applying for Social Security. Any more than 3 hours a week can put your application in some jeopardy. Even the 3 hours may be questioned. After you've been accepted, the rules change, and you are allowed to work a certain amount without immediately jeopardizing your benefits. (The rules for this system are complex, and if you are granted benefits you must learn them thoroughly before doing any work, so that you will know what can happen to your benefits under various conditions of work/earnings).

If you have to work a few hours a week to make ends meet, you should consult an advocate or attorney who knows about Social Security disability for an opinion about how your work will affect your application.

What programs are available to an individual with few or no resources during the Social Security waiting period?

General Assistance

"General Assistance" is a generic term that has different specific names in different states. In Massachusetts, the assistance program is Emergency Aid to Elderly, Disabled and Children (EAEDC). It is available from the State Department of Transitional Assistance. (In most states it is the Public Welfare Dept.) Depending on the state, you obtain a form from your doctor stating that you are disabled for a specific number of months. This program is only for people with almost no income or assets. In Massachusetts, the limit on monthly income is about \$300, and this is also the monthly payment. There is also an asset limit, which may or may not include a car. The program includes immediate *Medicaid/Mass. Health insurance*. You should be eligible for *food stamps and fuel assistance*.

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Unemployment Compensation

Sometimes when a person can no longer work, s/he is laid-off or terminated. Given that Social Security can take months to be approved, the individual may instead seek unemployment benefits. Generally, a person who is laid-off is eligible. A person who is terminated may be eligible if the termination is not his/her fault, and the employer does not contest the benefits. A person who resigns is generally not eligible, unless s/he can show the resignation to be compelled. If you have resigned, you should check carefully as to your rights to unemployment compensation.

The issue of whether an ill or sick person can receive unemployment benefits is not a simple one. To be eligible, a person must be willing and able to work—and be seeking work. Unemployment compensation, under some circumstances, allows a partially ill person to obtain benefits; there is some leeway for limited, partial disability. Perhaps you can work part-time. You may need to check with a disability lawyer. However, you cannot apply for Social Security disability while receiving unemployment benefits, since your receiving unemployment benefits stipulates that you are able to work, while the criterion for receiving disability requires you to state you are totally unable to work.

Workman's Compensation

A number of patients with CFS/CFIDS/ME, FM, multiple chemical sensitivity (MCS), and toxic exposure apply for Workman's Compensation. To be eligible, you must be able to show that an illness or injury was caused, or probably caused, by your employment. CFS/CFIDS/ME, an immune and neurological disorder, is sometimes caused by extreme work stress or exposure to toxic materials. If you believe that your illness was caused by your job, you should check with a workman's compensation attorney familiar with the type of illness you have. The workman's compensation procedure requires perseverance.

Disability Retirement

Various public employees, both at the state and local level, are not covered under Social Security. The local or state governments have disability retirement systems. If you are clearly disabled and can't work, you should determine whether you are eligible to take a disability retirement. Most jurisdictions require a certain number of years worked—or to be "vested"—often ten years. For instance, the only "disability retirement" for those under the GIC Commonwealth of Massachusetts retirement plan is the raising of the "age" of the applicant to 55, if you are under the age of 55. This means retirement benefits (if you are vested) will be computed based on the creditable years worked with the system's percentage multiplier for someone of age 55. If you are age 55 or over, you must take normal retirement.

You will likely need the advice of an attorney to guide you through the disability application process. If you are in a labor union, you might be able to find an attorney familiar with obtaining disability retirement through your union; however, you may have to educate him or her about CFS/CFIDS/ME or FM. You may want to hire a private attorney who knows about the illness and the retirement system. Usually you will have to obtain very thorough medical documentation to persuade a medical board and/or the retirement board of your condition.

More Resources

[*Attorney Fee Agreements for Disability Claims: What is a Fair and Legal Agreement*](#)

[*Disability Benefits, Fibromyalgia and CFIDS: What you don't know could be fatal to your claim!*](#)

[*Disability Insurance Claims: General Information*](#)

[*Obtaining Disability with CFS*](#)

