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This section provides information on the programs of private and public sector assistance to individuals who are suffering from the partial or total inability to work due to the disabling effects of chronic illness.

For those whose chronic illness would allow them to continue working provided they could obtain a change in work routine, tasks, hours, or type of work, the federal Americans with Disabilities Act and comparable state laws require many employers to reasonably provide such “job accommodation” to enable disabled individuals to continue working.

For those individuals who are unable to continue working at all, or only very minimally, and who need income, health insurance, housing and other assistance, various federal, state, and private sector programs are available to help meet these needs.

Chronic Disability and the Inability to Work

Normally, at the onset of the Chronic Fatigue Syndrome/Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFS/CFIDS/ME) or Fibromyalgia (FM) the individual has been healthy and fully or partially employed in his/her occupation or profession. As the illness continues or worsens, the individual tries with increasing difficulty to maintain his or her original level of work in order to maintain the necessary income and health insurance to meet his/her costs of living. However, continuing full time or part time work often takes an increasing toll as the individual cannot expend the energy required, and the illness is exacerbated.

There is a general distinction between the level of disability between CFS/CFIDS/ME and FM. First, CFS/CFIDS/ME and FM, while overlapping illnesses, are different illnesses. *On average,*

CFS/CFIDS/ME is more disabling than FM. CFS/CFIDS/ME patients are usually moderately to seriously ill and therefore may be unable to continue working full time, if they are able to work at all. Moderately ill FM patients may be able to continue working full or part-time, especially if aspects of their jobs can be changed. Severely ill FM patients may be unable to work at all.

Experience shows that an individual's experience with CFS/CFIDS/ME and FM and the inability to work often falls into one of three categories

1. The patient whose illness is of moderate or lesser severity who is able to continue working over a continuing length of time without making the illness worse—but often only if there is some reduction of work load/work tasks.
2. The patient who becomes acutely ill with severe symptoms who does not improve, and who despite trying to continue to work at his/her job, finds out fairly quickly that s/he cannot manage to do so. This person is so sick that more and more days must be taken off. After some weeks or months, despite determined efforts, arrangements may be made to work part-time with a less strenuous set of work tasks. Finally, before too many months pass, the patient finds s/he cannot keep the job under any conditions.
3. The third group of patients, after becoming ill, continues to work over a long period of time—although they are often very sick. They push themselves to get up and go to work, despite being sick. They come home exhausted, have a quick dinner, and go to bed —only to repeat the pattern. Sometimes they have better periods; other times they are worse. They may have to cut back on hours and take many days off—but for economic and other reasons they continue to make superhuman efforts to continue. However, they also realize they are keeping themselves from getting better or are making themselves worse. As time goes by, sometimes years, they are on a descending curve—their illness is getting worse and the effort to continue is becoming too great. At this point, the person's body begins to give them no choice but to stop working. Or, before this point is reached, the person realizes that to continue working is truly jeopardizing his or her long-term health, and it would be better to stop working in order to try to facilitate recovery over time.

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Many individuals who are moderately or less ill can continue to work without chronic harmful consequences—but only if they are able to alter the conditions of their work. The approach to use is "job accommodation". A person could maintain his or her ability to work over time if s/he could reduce the number of hours and/or the nature or severity of the job tasks/work load. Perhaps s/he could work from home one or two days a week. *A person with a valid disability may claim the right, in many cases, to job accommodation under state and federal disability laws.* *The Americans with Disabilities Act* and similar state laws grant the right to job accommodations for certain types of employment.

Employers covered by these laws are required to make "reasonable efforts" to assist the employee to maintain his or her employment by adjusting work conditions to accommodate the disability. However, the employer is only required to make such accommodations that are reasonably permitted by its business operations. Often larger businesses are better able to make such accommodations.

Therefore, for the person with CFS/CFIDS/ME or FM who is physically and mentally able to continue working with work accommodations commensurate to his/her symptoms and illness, job accommodation is the route to take. A prudent person will become aware of his/her legal rights and the practice of the employer before making direct requests for changes in working conditions or asking for a job transfer. *The Massachusetts CFIDS/ME & FM Association can assist patients with CFS/CFIDS/ME or FM with some resources and counseling in the area of job accommodation.*

If the employer is covered by the law and does not make a good faith effort to assist the employee, or tries to unfairly terminate the employee, there are remedies under the various laws. For instance, a complaint may be made to the federal agency that enforces the *Americans with Disabilities Act*

. States also may have agency enforcement mechanisms. In Massachusetts a complaint may be filed with the Massachusetts Commission Against Discrimination. In such cases, competent legal advice is required.

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If a person is so sick that s/he cannot continue to work at all, or work consistently enough to meet basic financial needs, then s/he must use disability income and medical insurance programs. For many patients their economic survival may depend on obtaining all available assistance.

First, a note on a topic that has frequently arisen with patients who have tried, via superhuman efforts, to continue working. There is the drive to continue working, no matter how difficult and how severe the physical and mental effects. In our work-ethic society, a person's intrinsic value is often thought of in terms of his/her work. To be chronically ill or disabled often has a strong connotation of having less value as a person. Traditionally, people who are not working are sometimes considered malingerers or lazy. Society often casts a disapproving eye on those who legitimately can't work. And as we are conditioned to this point of view, many of us will feel ashamed of not being able to work—even if we are really sick and are making ourselves worse by continuing to try to work. There are, of course, financial imperatives that push us to keep working to meet our expenses, especially if we have no other means of support for ourselves or our families.

To realistically counter the work-ethic imperative, we remind people that one's intrinsic worth—no matter what society says—is not based on having a job, but on being born a unique human-being. One is precious without regard to this or that job. Now it is a natural state that if one is healthy and can work, s/he wants to contribute to society. *But if someone is too sick to work, that is OK.* Being really ill is a simple fact without moral content. Then one's job is to take care of one's self with whatever assistance family, friends, communities and our nation can make available. All disability programs are essentially "insurance" programs. Anyone can become chronically ill, so as a society we mutually make a decision to spread the risk around. Everyone pays something into a vast pool, knowing this makes it possible to be helped when in need. So if you need to go on disability, realize that you have paid for your insurance—either directly or indirectly through premiums, work, or taxes. It is no shame to avail yourself of an insurance policy in time of need. Beyond this, a society that takes care of those truly in need is the kind of society we should all want to live in.

At some point, for the seriously ill patient, one of two things often happens. Either illness leaves no choice—it is physically and mentally impossible to continue to work—or s/he has not yet reached the collapse point, but knows that it will happen soon. So s/he recognizes it would be better to make an intentional decision to go on disability rather than being forced to when even more damage has been done to his or her health.

When a person reaches this "balance point"—where s/he is eligible for a disability program or where s/he "could" continue working for awhile, but it is clear that such work is harmful—we suggest a taking stock of the course of the illness and considering stopping work and taking the time to put an emphasis on recuperation.

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Deciding one can no longer work, whether absolutely enforced or by relative choice, can be a frightening experience. Even when the steps to obtaining financial and medical assistance are clear and known, it can feel like jumping into the void. There seems to be no certainty that one will receive assistance. Will my employer be supportive; will the insurance company approve me for disability; how can I get health insurance? If I have to apply for Social Security Disability Insurance, Supplemental Security Income, or Medicaid, how do I know I will be accepted and how will I live until I am approved?

The uncertainty, initially, in these questions can be scary and daunting. However, the facts are these: hundreds and thousands of disabled persons with CFS/CFIDS/ME and FM who can no longer work successfully receive various disability financial and medical assistance—including housing assistance when necessary. These programs enable them to survive when they cannot work. Other programs are also available when necessary, including housekeeping and homemaking services.

The keys to availing one's self of these programs is to first learn about them, and then to learn how to successfully navigate the necessary steps to use them. There are two important imperatives—persistence, and pacing oneself during the ongoing process.

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This section provides links to more resources on this topic. Some documents in this section may require Adobe Reader, which is available as a [free download](#), to be installed on your computer.

Updated information regarding the 2014 Social Security Disability Ruling

[*The 2014 Social Security ruling for Chronic Fatigue Syndrome*](#)

[*Analysis of the new ruling*](#)

[*Update on issues regarding Disability for CFS, FM, and Lyme Disease*](#)

[*MassCFIDS/ME & FM Disability Handbook: "How to Obtain Social Security Benefits if You Have Chronic Fatigue Syndrome \(CFS/CFIDS\)"*](#)

[*Disability Discussion - Barbara Comerford, ESQ.*](#)

[*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*](#)

[*Tips for FM Patients Applying for Social Security Disability*](#)

For information not covered here, please [contact us](#) .

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