

Mark Bronstein  
Law Office of Mark Bronstein  
288 Walnut St, Ste 120  
Newton, MA 02460  
Tel: 617-244-5551  
mark@bronsteinlaw.com  
www.bronsteinlaw.com

# DISABILITY AND EMPLOYMENT PROTECTION FOR PEOPLE WITH SCLERODERMA

**By Attorney Mark Bronstein**

## INTRODUCTION

The ability to work is a powerful force in our culture, both as a basis for economic independence, as well as an important element of our personal identity, self-confidence, and sense of accomplishment. On another level, people's differing attitudes about working reflect the broad spectrum of political perspectives on social class, the distribution of wealth and the proper role of the government in helping to support those individuals who for a variety of reasons are not self-sufficient. Intense and contradictory attitudes about working affect everyone in the disability process from the policy makers who design and administer the programs, the doctors who are asked to give opinions on their patients' disability, the agency decision makers, the claimants' families and the often ambivalent claimants themselves.

It is worth keeping these bigger issues in mind when talking about disability programs. Like it or not, they are always lurking just beneath the surface.

## SCLERODERMA AND DISABILITY

Just because you have been given a scleroderma diagnosis does not mean you cannot work. Whether you have difficulty working will depend on the nature and severity of your particular medical problems and the functional limitations which result. People with scleroderma may generally be able to function well enough to work, but may have periods of time when complications keep them from being able to keep working until things improve. Others may reach a point when their illness reaches the point that they are unable to keep working and do not expect to be able to return to work.

In either of these patterns of illness, your impairments can interfere with or completely prevent you from working temporarily or longer. This paper will cover the various programs that can help provide you with some financial support when you are not able to work. In addition, a number of programs which may assist you in staying at work despite your medical problems will be discussed.

## WHAT IS SSDI? WHAT IS SSI?

The Social Security Administration (SSA) administers two cash benefit programs for disabled people: Social Security Disability Insurance (known as "regular Social Security" or SSDI); and Supplemental Security Income Benefits (SSI). The two programs are often confused.

**Fewer years of coverage are needed for SSDI eligibility if you are under 31 when you become disabled.**

**SSDI** is a program which allows disabled people to collect their full Social Security retirement benefits without having to wait until they reach "full retirement age" (currently 65 ½ and climbing!). Benefits are payable to people who have worked in jobs covered by the Social Security system for 5 out of the 10 years before becoming disabled. To get credit for a full year of coverage in 2006 requires one to have earned \$3,880 in gross wages this year. Lower wages would give you only partial credit for the year. The amount required goes up every year.

**The SSA sends out a yearly earnings statement and benefit estimate which will tell you if you have enough quarters and what your benefit would be if you were to apply.**

The actual monthly SSDI benefit received is based on your total Social Security earnings since age 21. The more years you worked and the higher your earnings during your work life, the higher your benefit will be, although there is a maximum benefit, which was \$2,053 per month for individuals becoming entitled in 2006.

In addition to the benefit paid to the disabled wage-earner, **auxiliary benefits** may be paid to a the wage-earner's spouse and children. The total benefits payable to auxiliaries is usually 50% of the wage-earner's benefit.

**The current SSI resource limit is \$2,000 for an individual and \$3,000 for a couple.**

There is a 5 month waiting period after becoming disabled before a person is eligible for SSDI benefits. Up to a year's back benefits are payable for months of disability before the application is filed. After the disabled worker has received SSDI for 24 months he or she will be entitled to **Medicare** health coverage.

**The current SSI Federal Payment Standard is \$603 per month plus a state supplement which varies state to state.**

**SSI benefits** are paid to people who lack the necessary work history for significant SSDI benefits. The SSI program has an asset limitation and a household income limitation for eligibility. There is no waiting period for SSI, but no benefits may be paid for months prior to the month of application. Some people may be entitled to both SSDI and SSI if their SSDI check is small and they meet the other financial eligibility requirements for SSI. SSI recipients are also eligible for immediate **Medicaid** health benefits..

## THE CLAIMS PROCESS

Claims may be filed by telephone (800-772-1213), over the internet ([www.ssa.gov/disability](http://www.ssa.gov/disability)), or in person at one of SSA's local **District Offices**. The claims process is identical for both the SSDI and SSI

**Keep a written record of all conversations with SSA personnel including the name of the person you speak with. Important conversations should be confirmed in writing. Also, keep copies of anything sent to the SSA.**

programs. The claim forms elicit information about your family members, vocational background, and a detailed medical history with the names of all relevant medical providers. In addition, for SSI claims, detailed financial information to determine financial eligibility is required.

After the forms are completed, the file is sent by the District Office to the **Disability Determination Service (DDS)**, a division of the Massachusetts Rehabilitation Commission. There, claims examiners are supposed to send for all your medical records and contact your doctors. Depending on whether they get what they consider an adequate response from your doctors, they may also send you for a “consultative examination” with a physician and/or psychologist. After all the information is gathered an in-house doctor at DDS reviews the file and makes a decision about whether you meet the definition of disability. Usually, this is within about 3 to 6 months of when you filed. If the claim is denied, you have 60 days to file a **Request for Reconsideration**. The file then goes back to DDS for another review which can take another few months. If you are again denied you have 60 days to file a **Request for Hearing** before an **Administrative Law Judge (ALJ)**. There is a significant delay in scheduling hearings and you may wait from six months to a year before you get a date for a hearing before an ALJ.

It is at this hearing that most people who are initially denied benefits and who pursue their claims ultimately prevail. The ALJ will review the medical evidence that was previously considered as well as any other medical or documentary evidence you or your attorney submits. The judge will ask you questions about your past work and how your illness affects your daily activities. If you bring any other witnesses, such as your spouse, roommate, or a former co-worker who observed your difficulties on the job, they will have an opportunity to testify as well. A medical or vocational expert may also be asked by the ALJ to testify about the nature of your condition and about whether there are jobs which you could do despite your impairments. After the hearing, the judge will send you a written decision. If it is a denial, you have 60 days to file a written appeal with the **Appeals Council**. If the Appeals Council affirms the denial, you then have 60 days from receipt of the Appeals Council’s denial letter to file a complaint in federal court seeking to have the denial reversed or sent back for further consideration.

## **APPEAL, APPEAL, APPEAL!**

Social Security received over 2.5 million initial applications in 2004. Most claims are routinely denied at the initial level. Nationwide, 63% are denied at this first level, and claims are even more likely to be denied at the reconsideration stage. Many disabled people do not pursue their claims beyond this level because they are worn down by the system and become discouraged.

However, the greatest success rate occurs at the hearing level. The national statistics are that 62% of claims are granted at hearing. For claimants with experienced legal advocates, the success rate can be much higher.

It is important to file each of your appeals in the 60 day period following receipt of the notice of denial. A claim which has to be refiled because an appeal deadline is missed can result in substantial loss of back benefit payments. Having said that, there are situations where old applications can be revived even though appeals were never filed. If you file a current application, and at any point in the past had filed another application which was denied and never appealed, request that the earlier application be **reopened** and considered along with the new application. In some cases this can result in the receipt of many years of additional retroactive benefits.

### **WARNING! SSA ISSUES NEW RULES FOR CLAIMS FILED AFTER AUGUST 1, 2006**

**As this article went to press, the SSA was rolling out major changes to the SS claim application and appeal process. Some of the changes may help lessen the long delays currently experienced by claimants, particularly on cases under appeal and awaiting hearing. However, other changes may make it harder to establish entitlement to benefits by limiting claimant's right to submit medical evidence at the hearing level. Affected individuals are advised to seek expert advice on dealing with the new rules as early in the process as possible, or even before.**

**Details of the new procedures are just being released and are very much in flux. Anyone applying for benefits after August 1, 2006 would be well-advised to seek assistance from an experienced SS attorney who is keeping up with the latest developments.**

**The less education you have and the older you are, the less the SSA expects you to adapt to work that is not similar to what you have done in the past.**

**Prior to the hearing level, serious consideration is generally not given to claimants who do not have severe organ involvement, but whose primary limitations are caused symptoms such as pain and fatigue. This accounts for the high reversal rate when claimants persevere and appeal their cases to an ALJ hearing.**

## **DISABILITY AS DEFINED BY SOCIAL SECURITY**

Both SSDI and SSI have the same disability requirements. A person must show that as a result of medical problems he or she is unable to work and that this disability is expected to last at least 12 months or result in death. The jobs considered by the SSA include any job you have worked at in the last 15 years, or other work “which exists in substantial numbers” which you could be expected to adapt to given your age, education and past work experience. It does not matter whether there are job openings in your area, just whether there are jobs which you are capable of performing despite your medical impairments. You must be able to do the job such that it is considered “substantial gainful activity.” It is not enough to be able to do a suitable job on your good days or with significant special accommodations. You need to be able perform the job as it typically exists **full time on a predictable basis without excessive absenteeism.**

## **THE SSA’S EVALUATION OF SCLERODERMA AS A DISABLING CONDITION**

Just because a person has scleroderma does not mean he or she is disabled from working. The issue is whether a particular person’s symptoms and impairments result in limitations of daily function which make working on a reliable basis impossible.

The SSA has a multi-step process for determining whether a person meets the SSA’s definition of disability. Assuming the claimant is not working, the SSA will first consider whether the claimant’s condition meets or equals the clinical findings contained in the **Listing of Impairments**. The listing for scleroderma requires that the patient meet one of the following criteria: 1) very severe organ involvement, or 2) Lesser involvement in two organ/body systems, with one at an least “moderate level of severity” along with “significant, documented, constitutional symptoms of severe fatigue, fever, malaise, and weight loss,” or 3) a diagnosis of generalized scleroderma with digital contractures, or 4) severe Raynaud’s with digital ischemia, ulcerations or gangrene.” A copy of the full text of the listing for scleroderma is attached to this article

However, even if a person is not sick enough to meet the listings (which is a good thing!), her or she can still qualify for benefits at the next step of the claims analysis process which looks at whether the functional impact of all of the claimant’s impairments prevents him or her from

**When you see your doctor for your periodic exams, fully describe the extent of your symptoms and the ups and downs of your condition. Make sure this information goes in the chart on a regular basis.**

performing past work or other vocationally relevant work. This test, which allows for the full consideration of all of the claimant's symptoms, is the basis of most favorable decisions at the hearing level.

Therefore, for people who do not meet the above criteria, but who are nevertheless unable to work, the key to establishing entitlement is documenting all of their impairments which often include fatigue, pain, shortness of breath, problems with the extremities and cognitive problems.

It is also important to document the ups and downs of one's symptoms. Many patients will say that while on a good day, they could probably do some kind of easy job, their good days occur unpredictably and are interspersed with many bad days on which they can barely get out of the house. This pattern would clearly preclude most jobs as employers generally require a minimum level of reliability in order to keep an employee working productively. Similarly, some people with scleroderma can perform their "activities of daily living" fairly well, but only by avoiding difficult activities, taking it easy most of the time, lying down and resting periodically during the day and pacing themselves. If they were to be in a work situation where they had to go to a job to a regular schedule and could not rest as needed on a daily basis, their symptoms would be likely to worsen.

Side effects and complications of any medications being taken must also be considered. If a medication is successful in keeping the progression of a person's disease in check but causes quite debilitating side effects or complications, the person may be disabled despite the success of the treatment. The SSA's regulations specifically recognize the prevalence of steroid-related problems due to their frequent role in the treatment of scleroderma.

In summary, if your condition is such that you probably are not going to meet the listings, the key to establishing your entitlement is getting strong support from your physicians that despite the lack of severe gross motor neurological involvement, you do have significant fatigue and other symptoms which would make it difficult for you to work at a job outside of your home for regular hours on a sustained predictable basis without excessive absenteeism.

## **PRIVATE OR GROUP DISABILITY INSURANCE**

In addition to Social Security, consider whether you might be eligible for short term or long term disability insurance coverage maintained by

**Get a copy of your employee personnel and benefit booklet so you will know what your actual coverages are.**

your employer or through an individually purchased private disability insurance policy. The requirements for benefits under these policies are often more lenient than those of the SSDI program. Many policies cover shorter term disabilities than SSDI and will allow you to collect for the first two years of disability as long as you cannot do your own occupation, even if you can do some other kind of work. Then after two years of benefits, you may continue to collect if you meet the stricter SSDI disability standard of whether you can do any other job as well. Also in contrast to SSDI, some private policies will allow you to collect partial benefits if you are working but earning less due to your condition. Each policy will have its own rules and requirements, and policies differ dramatically regarding their coverage and requirements. You should request a copy of all relevant employee personnel manuals, benefit booklets and insurance policies so you can determine your actual coverages and the applicable rules.

If your claim for disability insurance is denied you can provide additional medical documentation and request that the insurer reconsider. You should pursue this option vigorously because if you are not successful, the only real appeal is to the courts, which can be time-consuming and expensive. In addition, while individuals with individually purchased disability policies can sue using the state consumer protection laws which provide for payment of attorney's fees and penalties against insurers who unreasonably deny claims, people whose disability coverage comes as part of their employer's group benefit plan, are restricted to the more limited remedies provided by the federal **ERISA** pension law.

## **CONSIDER ELIGIBILITY FOR OTHER DISABILITY PROGRAMS**

In addition to Social Security and private disability policies, consider whether you might be eligible for some of these other disability programs:

- Employer or union sponsored disability pension benefits.
- State workers' compensation benefits where a work-related injury can be shown to have exacerbated your condition.
- Loan or mortgage deferral, or life insurance premium deferral based on your disability.

- Unemployment benefits where you had to leave your last job due to your health, but where you can still do other less demanding work, but just have not been able to find a job.

Each disability program will have its own rules and requirements, and each may differ dramatically regarding:

- Application and documentation requirements.
- Extent of disability, i.e., if disabled from usual work whether you would be expected to perform other less demanding work.
- The required duration of the disability.
- Non-medical requirements such as limits on assets or income.
- Appeal rights and procedures if benefits are denied or terminated.

## **MAINTAINING HEALTH INSURANCE**

Maintaining health insurance coverage is a critical issue for people with scleroderma, especially if they become disabled and have to stop working. Employers' policies on continuation of health benefits during periods of disability vary greatly. While some employers may have personnel policies providing for continuation of coverage for some period of time after active employment ends, coverage will probably end sooner or later. Your employer's personnel policy, and/or union contract, should be reviewed to determine how long, if at all, coverage will continue.

If the employer has at least 20 employees, the federal **COBRA** statute requires the employer to allow you and your family to stay on the group health plan for 18 months, although you must pay the entire monthly premium yourself. If you are found entitled to Social Security Disability benefit before the 18 months is up, the period can be extended up to 29 months, which is ordinarily when Medicare coverage would start.

If due to your scleroderma, you will be out of work, but you only expect to be out for a short period of time, and your employer has at least 50 employees, the federal **Family Medical Leave Act** requires that you be given up to a 12 week leave of absence and that your health insurance coverage be maintained during the leave.

## **ACCOMMODATIONS TO ALLOW YOU TO KEEP WORKING**

While the focus of this paper is on getting benefits if you cannot work, many people with scleroderma could continue to work productively despite their impairments if their employers would make some adjustments in their job requirements. People with scleroderma may be protected by their state's employment discrimination law and by the Federal Americans with Disabilities Act (ADA). Depending on the circumstances, employers may be required to make reasonable accommodations to your illness-related limitations, such as adjusting your responsibilities, schedule, or other work requirements. Employers are also not allowed to single out employees who they unfairly regard as handicapped. For example, if your employer is aware of your illness and tries to hold you to a higher standard of productivity or attendance than is required of other employees, you may have a discrimination claim. Discrimination claims must initially be filed with the your state's discrimination agency (or in some states with the federal the Equal Employment Opportunity Commission (EEOC) and may be later taken to court. In some states, there is a very short statute of limitations, and claims may have to be filed within as little as **6 months** of the employer's alleged discriminatory act. Check your state laws for the local requirement.

**Watch out for the very short statute of limitations for filing a discrimination claim! Seek legal advice to determine what the deadline is in your state.**

**Employers may not deny FMLA leaves because it would be inconvenient or because the employee is "too important".**

**Employers may not use FMLA leave as a basis for discipline or discharge, or as a reason for denying a promotion.**

One weakness of the handicap discrimination laws is that it is not clear that its provisions require employers to accommodate ongoing erratic attendance or periodic month long absences, a pattern familiar to many people with scleroderma. However, for patients and their immediate family members working for public and private sector employers with more than 50 employees, since 1993 the federal **Family and Medical Leave Act**, has provided important new protections. This law guarantees the right to up to 12 weeks of unpaid sick leave per year needed due to the employee's own serious illness, or to take care of a parent, spouse, or minor child with such a condition. As discussed earlier, employers must maintain employees' existing health insurance during FMLA leaves. Upon return from an FMLA leave, the employee must be put back in their regular position or to a similar position at the same pay.

Medical leaves under the FMLA may be taken on an intermittent or part-time basis. This could allow a person with scleroderma up to 12 weeks of sick time per year without getting discharged for excessive absenteeism. Alternatively, if your doctor has restricted you to part-time work, you would be entitled to a half time schedule for 24 weeks (equivalent to 12 full FMLA weeks) per year. As discussed earlier, employers must maintain health insurance coverage during FMLA leaves.

## **ABOUT THE AUTHOR**

Mark Bronstein has been representing individuals in disability claims since he graduated from Northeastern University School of Law in 1980. He regularly handles claims for Social Security Disability, SSI, private and group disability insurance, workers compensation, and also provides consulting to chronically ill individuals on benefits planning, health insurance, job accommodation and related issues.

Mark has a longstanding relationship with the Scleroderma Foundation and has spoken at a number of national conferences over the years. An earlier version of this paper was published in *The Best of the Beacon* (1999).

He was a member of the Board of the Lupus Foundation of New England from 1988-2005. Other illness support organizations with which Mark has worked include the National Multiple Sclerosis Society, American Sleep Apnea Association, the National Narcolepsy Network, the Boston Self Help Center, and the Leukemia-Lymphoma Society.

He has been a frequent presenter on disability issues at continuing legal education seminars sponsored by organizations including the Massachusetts Continuing Legal Education Institute, the Massachusetts Bar Association, the Boston Bar Association, the National Organization of Social Security Claimants' Representatives (NOSSCR) and the Massachusetts Disability Law Center.

Comments and questions are welcome and can be directed to him at:

Law Office of Mark Bronstein,  
288 Walnut St, Ste 120, Newton, MA 02460  
(617)244-5551  
email: [mark@bronsteinlaw.com](mailto:mark@bronsteinlaw.com)  
[www.bronsteinlaw.com](http://www.bronsteinlaw.com)

©Copyright 1996-2006 Mark Bronstein. All rights reserved.  
(July 24, 2006)

## EXCERPTS FROM THE SSA'S LISTING OF IMPAIRMENTS RELEVANT TO SCLERODERMA

### 14.00 Immune System

\*\*\*

B. Dysregulation of the immune system may result in the development of a connective tissue disorder. Connective tissue disorders include several chronic multisystem disorders that differ in their clinical manifestation, course, and outcome. They generally evolve and persist for months or years, may result in loss of functional abilities, and may require long-term, repeated evaluation and management.

The documentation needed to establish the existence of a connective tissue disorder is medical history, physical examination, selected laboratory studies, appropriate medically acceptable imaging, and, in some instances, tissue biopsy. Medically acceptable imaging includes, but is not limited to, x-ray imaging, computerized axial tomography (CAT scan) or magnetic resonance imaging (MRI), with or without contrast material, myelography, and radionuclear bone scans....

A longitudinal clinical record of at least 3 months demonstrating active disease despite prescribed treatment during this period with the expectation that the disease will remain active for 12 months is necessary for assessment of severity and duration of impairment.

To permit appropriate application of a listing, the specific diagnostic features that should be documented in the clinical record for... systemic sclerosis and scleroderma ...

In addition to the limitations caused by the connective tissue disorder per se, the chronic adverse effects of treatment (e.g., corticosteroid-related ischemic necrosis of bone) may result in functional loss.

These disorders may preclude performance of any gainful activity by reason of serious loss of function because of disease affecting a single organ or body system, or lesser degrees of functional loss because of disease affecting two or more organs/body systems associated with significant constitutional symptoms and signs of severe fatigue, fever, malaise, weight loss, and joint pain and stiffness. ...

3. Systemic sclerosis and scleroderma (14.04)—These disorders constitute a spectrum of disease in which thickening of the skin is the clinical hallmark. Raynaud's phenomena, often severe and progressive, are especially frequent and may be the peripheral manifestation of a generalized vasospastic abnormality in the heart, lungs, and kidneys. The CREST syndrome (calcinosis, Raynaud's phenomena, esophageal dysmotility, sclerodactyly, telangiectasia) is a variant that may slowly progress to the generalized process, systemic sclerosis, over years. In addition to skin and blood vessels, the major organ/body system involvement includes the gastrointestinal tract, lungs, heart, kidneys, and muscle. Although arthritis can occur, joint dysfunction results primarily from soft tissue/cutaneous thickening, fibrosis, and contractures.

\*\*\*\*

14.04 Systemic sclerosis and scleroderma. Documented as described in 14.00B3, with:

A. One of the following:

1. Muscle involvement, as described under the criteria in 14.05; or
2. Respiratory involvement, as described under the criteria in 3.00ff; or
3. Cardiovascular involvement, as described under the criteria in 4.00ff; or
4. Digestive involvement, as described under the criteria in 5.00ff; or
5. Renal involvement, as described under the criteria in 6.00ff.

or

B. Lesser involvement of two or more organs/body systems listed in paragraph A, with significant, documented, constitutional symptoms and signs of severe fatigue, fever, malaise, and weight loss. At least one of the organs/body systems must be involved to at least a moderate level of severity.

or

C. Generalized scleroderma with digital contractures.

or

D. Severe Raynaud's phenomena, characterized by digital ulcerations, ischemia, or gangrene.

Reprinted from the SSA regulations, 20 CFR, Part 404, Appendix 1 by:

Law Office of Mark Bronstein  
288 Walnut St, Ste 120  
Newton, MA 02460  
Tel: 617-244-5551  
[mark@bronsteinlaw.com](mailto:mark@bronsteinlaw.com)  
[www.bronsteinlaw.com](http://www.bronsteinlaw.com)

Important Note from MB: While meeting the above criteria will result in the automatic approval of a claim for benefits, even if an individual's condition does not meet the above criteria, they may still be found to be disabled based on the severity of their symptoms and the effect of these symptoms on their ability to work at a full time job on a sustained reliable basis.