



BY LISSA POIROT

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Mary Ford hasn't been able to work full time since 2003. That year, the Washington state resident, with the support of her neurologist and the other physicians she saw for her MS issues, filed for Social Security Disability Insurance benefits (SSDI). She was denied. Why? Although she could no longer work as a senior project manager for a design/build firm, SSDI reviewers felt she could do less taxing work elsewhere.

Ford took a part-time job at a church. Migraines, fatigue, and pain caused her to miss many days. Then an MS attack hit and she couldn't read, write, or hold a conversation. She asked the Social Security Administration (SSA) for reconsideration and was denied again. SSA rules say a qualifying disability is "permanent." Continuing to work when she could, Ford experienced leg pain so severe she couldn't walk. Last May she resigned her position, hired an attorney, and again applied for SSDI. It wasn't until the year was drawing to a close that Mary finally received approval. This January, just as her landlord handed her an eviction notice, she got her first check.

Ford's story is a common one. A 2006 report from the National Multiple Sclerosis Society found that nearly half of the people with MS applying for SSDI were denied at least once before being accepted. Others report two or three denials before receiving acceptance. Still others simply give up.

Social Security nuts and bolts

It sounds easy enough: work hard and pay taxes, and in the event that disability occurs before retirement age, Social Security will pay disability insurance benefits, or SSDI. But it is not so easy.

First, applicants must have worked for a specified length of time in jobs that were covered by Social Security; they must currently earn less than \$900 per month (the limit is higher for those who are blind); and they must have MS symptoms so severe that they are prevented from working. That means **any** kind of work. Perhaps a person can no longer work as an accountant but has "transferable skills"

for another type of job. For example, the former accountant could work as a ticket-taker at a movie theater. If so, that person doesn't qualify for SSDI.

Next, disability must be documented, and the burden of proof is on the applicant. An applicant with MS must be able to document one or more of these: 1) disorganization of motor function; 2) visual

An application punch list

- Visit nationalmssociety.org/SSDI for a complete guide to the application process.
- Keep a detailed journal of your MS symptoms and how they limit your ability to work.
- Visit your doctor and let her/him know you plan to apply for SSDI benefits. Offer your doctor the Society's template letters to make documentation of your symptoms easier.
- Don't delay if you cannot complete certain **general** information on the application. Sufficient **medical** information is the most important.
- Don't hesitate to ask for help from an SSA representative, the National MS Society office, a family member, or staff in your doctor's office.
- If possible, apply in person so that you have a contact for follow-up.
- Don't give up. Raymond LaFehr of Westland, Michigan, who rode a two-year denial rollercoaster before receiving disability benefits, put it well: "It was a long haul but worth the fight."



loss; 3) mental impairment; or 4) “significant reproducible fatigue of motor function with substantial muscle weakness on repetitive activity, demonstrated on physical examination.” The exact requirements are spelled out in the SSA’s “Blue Book” (SSA No. 64-039, or www.ssa.gov/disability/professionals/bluebook).

It may not be hard to document trouble walking or seeing, but fatigue, often the most disabling MS symptom, is another story. MS fatigue takes many forms, and some don’t fit the SSA description. “MS lassitude”—that all-out hitting the wall and becoming unable to function—doesn’t show up on testing of the muscles.

The SSA uses the term “residual functional capacity,” or RFC, for impairments that do not seem to meet their standards.

The SSA reviewers try to determine the RFC through medical and vocational documentation. This is a complex process to say the least, especially difficult for people whose symptoms fluctuate or are invisible.

The review process

From the date an SSDI application is received, the average time to approval or denial is three to four months. The odds of receiving an approval on the first attempt are not good for anyone. In

2004, more than 2.1 million initial claims were filed for all disabling conditions. Fewer than 800,000 were approved.

SSDI attorney Jeffrey A. Rabin of Rabin & Associates, LTD, in Des Plaines, Illinois, explained: “SSA almost never denies that a person has a condition. A guy has a scar six inches down his back; he had back surgery. A lady has plaque on her brain; she’s got MS. So what? People with back surgery work every day. People with MS work every day. The issue is, can you prove that the functional problems due to your MS are so severe that you can’t function in any kind of job at all?”

The winding path of appeals

If a first application is not accepted, appeals can literally stretch over years:

■ If you receive a denial from the SSA, you have 60 days from receipt of the letter to file for reconsideration. SSA will reply in four to six months.

■ If you receive a denial for reconsideration, you have 60 days to request an informal hearing that will be held before an administrative law judge (commonly called the ALJ). The ALJ will review your medical records, interview witnesses, and make a decision. Getting this hearing takes about a year, far longer in some jurisdictions.

■ If you receive a denial from the ALJ, you have 60 days to file an appeal with the Appeals Council, which will review the case and decide if you can have another hearing.

■ If the Appeals Council denies you a review, you have 60 days to file a lawsuit in a federal district court. A federal judge will review your case and choose one of three options: awarding benefits, denying benefits, or sending your case back to a lower court for an additional hearing.

Lawyer up—or not?

Many people, like Theresa LeBrun, turn to attorneys who specialize in SSDI appeals. Is this a good decision? The right answer depends on individual circumstances. An attorney will not be free. However, legitimate SSDI attorneys charge only clients who receive disability benefits, and their fees are regulated by the SSA.

Emily Hubbard of Madison Heights, Virginia, chose to hire a SSDI attorney after being denied twice. Her appeal was then approved. Her lawyer received \$2,000 of her settlement; she received \$14,000 and felt a huge relief at obtaining her benefits.

With or without a lawyer, people who have been through the SSDI knots stress the importance of slogging on. With well-prepared applications, better informed SSA review boards—and, hopefully by next year, new MS criteria, eligible people with MS may avoid the knots altogether.

But hearings do provide an opportunity to come face-to-face with the decision makers. These private meetings give officials an opportunity to talk with the applicant and listen to physician testimonies.

“The day of my hearing I was called into the conference room with about eight people, including me, my attorney, the hearing judge, and doctors who would tell the judge if my symptoms were related to my diagnosis,” said Theresa LeBrun of Griffith, Indiana. “I answered everything correctly and honestly. At the end of my hearing, the judge looked at me and said, ‘You should have never been denied in the first place.’ He granted my benefits right then and there. After two years of what felt like running a marathon, it was an unbelievable relief.”

Why so long and knotty?

It isn't just people with MS who find the system beyond frustrating. In response, the SSA is attempting an overhaul. Changes intended to speed up the process and afford applicants more and better opportunities to provide documentation have



the Society's associate vice president of Federal Government Relations. "We crunched the information further down, looking specifically at the claims by people with MS, and saw the variance was sometimes even greater."

"We also found that many physicians are unaware of the official criteria used to determine whether a person with MS is legally eligible for SSDI benefits," said Kim Calder, senior manager of

now been rolled out in New England. SSA plans to extend these reforms to the whole country. But these changes don't address the unusual aspects of MS. Moreover, what we have now will be around in many places for several more years.

What superhero could make it easier for our community? The Society didn't turn to anyone wearing a cape or tights. It established a task force of men and women who first plunged into the unglamorous work of acquiring and analyzing data.

"We saw that SSA's approval rates for disability benefits varied significantly by state and by region," said Shawn O'Neil,

the Society's Insurance Initiative.

The Society asked and the SSA listened

"In March 2006 I invited SSA officials to discuss our findings," O'Neil said. "Martin Gerry, SSA's Deputy Commissioner of Disability, attended with some of his staff. Representing the MS community were Joyce Nelson, Society Board members and executives, members of the American Academy of Neurology, and representatives from the Consortium of MS Centers. Mr. Gerry was very direct. The SSA wanted to improve its review process and invited the Society to provide MS expertise."

Private disability insurance has its own problems

A second Society task force, headed by Kim Calder, is examining private disability insurance. To learn more, go to nationalmssociety.org/insurance or call us at 1-800-344-4867.

In the interim, everyone agreed that both applicants and SSA reviewers could ease the process by knowing more.

Creating a more powerful claim

People planning to file for SSDI benefits are urged to visit nationalmssociety.org/SSDI first. A well-organized application with clear documentation of medical conditions by physicians has a much improved chance of being approved.

The Society is completing a new section of our Web site to help. It will debut this April or May. It will have clear guidelines on current criteria, evaluation checklists, and easy-to-use templates that can be downloaded or e-mailed to health professionals for those all-important physician letters. If the section is not ready yet—or you cannot access the Web—phone your chapter at 1-800-344-4867 to get materials by mail.

In addition to medical records, applicants are encouraged to submit journals or diaries about their MS symptoms, their daily activities especially at work, and how they impact each other.

Power pays off

"I spent 11 hours completing applications and writing essays that listed my doctors and hospitals, my appointment dates, and

why I see each doctor. I listed every medication, the side effects, and why I take each one. I summarized every job I've held for the last 15 years and included details of my daily activities. My application was approved on the first attempt. It took just six weeks. My case worker told me that my application and essays were the best she has ever seen," said David Sloan, of Colorado.

Developing a more receptive agency

SSA invited the Society to educate its employees about MS, especially the hidden impairments. Starting this April, a new educational video produced by the Society is being broadcast on SSA's satellite network. It will reach 1,500 offices across the country this year. Also this year, Society staff and professional volunteers began offering in-person presentations on MS at SSA conferences.

There's more. Society staff and volunteers are deeply involved in working with SSA staff to revise the criteria for MS disability claims and, importantly, to determine an appropriate "residual functional capacity," or RFC, for MS.

"Leading neurologists and nurses volunteered," O'Neil said. "The draft is now complete but the criteria need to pass a series of government reviews before they can be adopted. We believe they will be approved by the end of 2007," he reported. "The medical criteria haven't been changed in 20 years, even though what we know about MS has changed a lot in the same period." ■

Lissa Poirot is the former managing editor of **Arthritis Today**.