



WHAT YOU NEED TO KNOW ABOUT SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

By David Spero, RN

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“This is great,” said Joan, a member of my MS support group. “My life is so much better. Some days, I don’t feel like I’m sick at all.” What wonderful intervention made such a difference in Joan’s life and health? Hint: it wasn’t a drug. It was money: Joan recently started receiving Social Security Disability Insurance (SSDI).

Going out on disability is a challenging life change for some, but for the majority of people with MS, it comes as a lifesaver. “Receiving disability transformed my life in four ways,” Richard, another MS friend, told me. “I don’t have to use up all my energy (and then some) to get through a work day. I don’t have to struggle to appear less disabled than I am, or put up with harassment from supervisors. And most important, I don’t have to worry about losing my income and my home. I have so much less stress and more time to devote to keeping my body in the best possible health.”

While a few people might opt for disability too soon and become isolated and depressed, for most people with MS, the problem is waiting too long or not having disability resources available. The struggle to maintain income takes priority over self-care activities and finding other sources of help, and the stress causes exacerbation of symptoms. Health care professionals can and should help patients qualify for disability and live successfully with it.

Pros and Cons of Disability

People sometimes see going on disability as the beginning of the end. You’re out of the work force, in danger of becoming isolated with not much to live for. But in reality, going on long-term disability can be a key step in recovering health. “You don’t go on disability to die,” as one man told me. “You go on disability to heal.”



Others may feel guilty for taking government disability, as if they are “leeching on the government,” according to NMSS Direct Services Coordinator Rosemarie Johnson. She tells such people, “As long as you’ve worked, F.I.C.A. has taken money out of your paycheck. This is your money you’re getting back.”

Another problem is the actual application process. Patients have to fill out forms describing their condition in the worst possible terms. This can be very painful when you’ve worked hard to maximize your abilities and live your life as fully as you can. “At first, I was anxious because I felt I was exaggerating symptoms,” Joan told me. “Then it was very depressing when I realized I wasn’t.”

The whole process can cause suffering and stress. Social Worker Karen Weissmann of California Pacific Medical Center says, “It’s normal to grieve over the loss of our working identity. It’s normal to get professional help with that loss. And it’s also quite common to return to work after getting more support in place. So getting disability can be an important step in maintaining our productivity in the long run.”

Some people wonder what they will do if they cannot do a job. Some possibilities: retraining to work from home, spending more time on their health, taking up activities they always wanted to do, or used to do but gave up, spending more time with family, or just resting more. It’s valuable to remind people that there is a difference between work and a job. We can find what the Presbyterians call a “place of usefulness” in the world. People on disability might want to volunteer, or they might just want to enjoy themselves for a while. It will be important for them to stay in touch with people. Most people eventually find satisfying lives without working a job.

What does “Disabled” Mean?

The Social Security Administration (SSA) has made applying for SSDI more convenient and has somewhat standardized their formerly confusing rules for evaluating disability in MS. There is really only one criterion – can you do substantial paid work? Their standard for “substantial” is \$800 / month. And it doesn’t have to be work you are used to, or work that is available in your



community. Ability to do any kind of full time paid work at all can disqualify you. (One major exception: if you work for yourself, SSA looks at the net income – what you report to the IRS – not at your gross.)

There are five ways people with MS can prove their disability. Substantial limitation of vision, cognitive problems, fatigue, or major disability of two extremities will qualify an applicant as disabled. SSA can also use a combination of these factors, evaluated on what they call a “grid” of over-all disability.

Be Proactive

We normally don’t want to think about the possibility of being unable to work. But preparing for the worst in this area can make a tremendous difference in patients’ lives. Lawyer David Landay writes in *Be Prepared: The Complete Financial, Legal, and Practical Guide for Living with a Life-Challenging Condition*, “Preparing for the worst separates an informed positive attitude from simple blind hope...[it] enables you to maintain the kind of environment that will enable you to expect the best.”

For example, fatigue and cognitive problems are the most common qualifying disabilities for people with MS. But they are also hardest to prove on a physical exam or an interview. So people with MS need to prepare. Rosemarie Johnson says, “You have to be proactive. Start documenting your condition and how it affects you. Keep a journal and write down about your symptoms and how they limit your activity. See your doctors regularly. That way, if you do need to apply for disability, you’ll have solid documentation.”

Of course, journal writing has other health and psychological benefits, too. And reports of symptoms can be very helpful to doctors and others involved in care. Encourage patients to make written reports of symptoms and put copies in your medical records. Thad Smith, another MS counselor, says about dealing with government agencies like Social Security, “You have to remember you’re dealing with overworked bureaucrats. You have to provide the information they need to make a decision...letters from doctors, results of tests. Some people call when



they're in crisis, and they're not ready. That slows things up and makes it more likely they'll be turned down."

A good letter from a doctor testifying to fatigue or cognitive problems can sometimes guarantee that an applicant will receive disability. So doctors should ask about fatigue and cognition at each appointment, or patients should bring it up. It's helpful to get a neuropsychological evaluation every couple of years and again before applying for disability. Disability advocate attorney Dan Edelman says letters from family, friends or anyone who has observed your daily activities can also document your disability.

It's also proactive to buy disability insurance while you still can. SSDI often doesn't pay enough to maintain applicants' standard of living, so it helps to have private disability insurance to supplement SSDI. Some employers provide access to disability coverage. Patients should be encouraged to take advantage of this benefit. Outside insurers also sometimes sell policies, even to those with a preexisting illness

The Application Process

People can apply for disability on line at www.ssa.gov or by phone at 1-800-772-1213 or in person at a local social security office. There is a preliminary application form, on which applicants are asked to list their doctors and their work history. A few weeks later, applicants will receive a second "advanced form" that asks them to describe their daily activities and abilities in some detail. The form is in English, but the SSA has translators available for almost any language. Their on-line information pages are in 15 languages.

The process is emotionally draining, so it's a good idea to have a friend or family member help with filling out forms. (A major reason for applications being turned down or delayed is illegible handwriting.) Physicians and staff are not allowed to help fill out the forms. Applicants should fill out the forms truthfully, but report what it's like on a bad day, not on their best day. Sometimes, applicants need an outside person to remind them what a bad day is really like. Or someone at the Social Security office can help with the forms. SSA will solicit medical records from all doctors mentioned in the preliminary application (so applicants should know their names



and addresses.) Then SSA hires physicians to evaluate the application. If they have questions, they may send applicants to their own neurologist or psychologist for further evaluation.

About two-thirds of applicants with MS are turned down the first time they apply. Attorney Dan Edelman says “People often get disgusted and upset when they get turned down the first time. But they should almost always appeal.” There are four levels of appeal. First comes a paper review of the documentation SSA received. Next is an appeal hearing before an administrative law judge. If turned down again, the case can go to the SSA Appeals Council, and finally, to Civil Court. About 75% of applicants with MS eventually get their money.

Once a judgment of disability is made, SSDI benefits start five months after the date of disability (not the date of application.) It may take years for all the appeals to go through, but applicants will receive everything they are owed as a lump sum.

It may be advisable to get a professional disability advocate or attorney to help with the claim. They know how to phrase things and what evidence will meet the SSA’s criteria. Some advocates like to wait for the appeals hearing, but Edelman says it’s better to get an advocate for the first appeal, the paper review. “If you wait for the hearing, you may not have enough time to see the doctors you need to see,” he says. For example, he may send applicants to an MS specialist or a neuropsychologist if they haven’t seen one, and that can take time.

Generally, the advocates are a pretty good deal. Most of them charge only if they win (patients should insist on that), and by law, they can take only a maximum fee of \$5,200.

Life on Disability

SSDI is not a ticket to the high life. A person who was making \$40,000 – 50,000 per year will receive about \$1250 – 1350 per month. The maximum monthly payment is around \$2000, and there is a cost of living increase built in. For people at the lowest end, or for those who didn’t have enough work history to qualify for SSDI, there is Supplemental Security Income (SSI) to add a bit more.



These sums do not usually provide a comfortable living (unless you move to Costa Rica). However, people can earn up to \$800 / month on the side without jeopardizing their disability income. Those who bought disability insurance prior to becoming disabled will have more, of course.

Social Security Disability (SSDI) has one other important benefit. It confers Medicare coverage 29 months after the date of disability. And for those who cannot work a job that provides benefits or enough income to buy insurance, Medicare may enable them to continue as your patient.

Remember that SSDI is “Long-Term Disability”, NOT “Permanent Disability.” It may turn out to be permanent, but SSA’s Ticket to Work program may give people ways back into the economy. Tickets to Work include rehabilitation and vocational services, maintenance of Medicare after starting back to work, and a five-year grace period during which applicants can get their disability reinstated if their job doesn’t work out.

The option of working from home or having a home business is something you might want to suggest to patients. This often works for people with disabilities or chronic illness, because they can make their own schedule and their own rules. For purposes of maintaining disability eligibility, SSA considers net income after all expenses are deducted. In practice, this means that people can earn a considerable income while disabled, enough to have a decent, productive life.

Health care professionals and patients should not consider an application for long-term disability a failure or a catastrophe. It’s like a walker or a wheelchair, a form of assistance that can enable patients to maintain the best possible quality of life. People on disability insurance can and do contribute a great deal to society as volunteers, caregivers, family, neighbors, or friends. Applying for SSDI is not a decision to take lightly, but it is not the end of the applicant’s useful life. It can often be the beginning of a better, and in many ways a healthier existence.



Resources for Disability Information and Services:

1. David S. Landay, *Be Prepared: The Compete Financial, Legal, and Practical Guide for Living with a Life-Challenging Condition*, St. Martin's Press: New York 1998
2. Social Security Administration – (800) 772-1213.
TTY (800) 325-0778
www.ssa.gov
Have your social security number on hand when you call, and be prepared for a long wait. You can get a lot of questions answered on-line, and even apply for benefits there.
3. Centers for Medicare and Medicaid Services
(877) 267-2383 <http://cms.hhs.gov>
4. Disability Counseling (Level of expertise varies.) National MS Society
Web www.nmss.org
Check web or local directories for phone numbers
5. Advocates – Counselors – Check the Yellow Pages under “Attorneys – Social Security Law” or the section called “Social and Human Services” for a counselor.
6. Fatigue Diaries – These two sites have downloadable fatigue diaries, which are very helpful in demonstrating fatigue-related disability.
7. Paralyzed Veterans of America – www.pva.org. Select “search” and type in “fatigue diary.” http://www.s4lc.co.uk/bgdisplay.jhtml?itemname=o_managing&s=3. This is a cancer site, but you can use their diary form as well.