



# InsideMS

THE MAGAZINE FOR MEMBERS OF THE NATIONAL MS SOCIETY

## A PLACE IN THE WORKFORCE

### A Special Reprint

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## A CUP OF AMBITION

by Tamar Asedo Sherman

Could you work if you had  
training? transportation?  
special equipment?

If you had to give up your last job because of MS, if you are looking to enter or re-enter the work force, or even if you are currently employed but worried about the impact of MS on your job—you owe it to yourself to make a call to your state’s vocational rehabilitation program. Under federal law, every state has one. The formal name varies, but “voc rehab” generally offers amazing possibilities. To be eligible, a person must have a physical, mental, emotional, or learning disability that interferes with



Security Disability benefits. A 43-year-old construction worker who built houses for a living, Knight was diagnosed with MS four years ago, after his sensitivity to heat made him unable to continue working. He also experienced numbness, loss of balance, speech problems, cognitive difficulties, and loss of peripheral vision.

the ability to work. Invisible problems such as MS-related fatigue or cognitive problems are included in this list.

“Five people sitting in the room can all have MS, but the degree to which MS impacts their ability to work and the services they need are different for each of them,” said Erin Treadwell of California’s Department of Rehabilitation. “We make sure the person’s goals are reasonable and attainable,” she said. In most states, voc rehab staff seek flexible solutions to help people with MS gain or retain employment as full-time, part-time, or self-employed workers.

“We look at a person’s strengths, abilities, and capabilities to achieve whatever is the vocational goal,” said Rita Martin, deputy director of Indiana’s Vocational Rehabilitation Division.

George Knight of Muscatine, Iowa, was referred to his state’s voc rehab service when he applied for federal food stamps to help extend his Social

His dream was to open his own woodworking business. “I can build just about anything you can imagine out of wood,” he said. The Iowa voc rehab team helped him write a business plan, and he obtained a \$2,500 state grant to buy tools and lumber. Knight signed the papers and set up shop in his garage.

“My pipe dream turned into reality!” he exclaimed. “I don’t have to work for anybody. I work for myself. I couldn’t have done it without them.”

Knight’s home business means he can pace himself and work when he feels up to it—usually early morning before it gets hot and evening after the sun goes down. He continues to get Social Security Disability benefits and, as of 2001, could earn \$740 each month, **after** deducting all his “impairment-related work expenses”. These include the cost of whatever it takes to permit him to work.

Most state voc rehab programs offer job readiness training, job coach-

ing, job placement, mobility training, and assistive technology assessments. For people with MS, counselors try to find jobs that are indoors, can be performed sitting down, and are part-time or have flexible hours to accommodate fatigue problems. Most states encourage education or retraining within their own systems, at two-year and four-year state institutions. Many provide short-term computer training programs.

“We provide anything that helps someone go to work or maintain employment,” said Cecile Bentley, assistant administrator for field operations at Oregon’s Vocational Rehabilitation Division. Oregon takes a particularly aggressive approach through its Employed Persons with Disabilities program, or EPD. “The risk of losing Medicaid benefits is one of the major barriers to employment,” said Scott Lay, EPD’s coordinator. “People shouldn’t have to choose between employment and health insurance.” In Oregon, they don’t have to.

The state amended its Medicaid plan to allow people to have earnings that don’t count against them for Medicaid eligibility, after the “trial work period” is over. Federal law now allows every state to do this, although they are not mandated to. The benefits of an aggressive program are very clear to Scott Lay.

Sue Kuenzi, age 35, of Monmouth, Oregon, was working on a master’s degree in rehabilitation counseling when she was diagnosed with MS. “I



never anticipated that I would need voc rehab services,” she said. But when her health insurance wouldn’t cover disease-modifying treatment, Oregon’s EPD advocated for her to get Medicaid, which now pays for her Copaxone. To enable her to keep her job at a community college, EPD outfitted her with a scooter to get around campus, hand-controls for her van, and a lift to get the scooter into the van.

“If we didn’t provide this program, clients like Sue Kuenzi wouldn’t be working, and they’d just be in the system,” said Lay. “Most would be on Medicaid anyway. This program allows the people to work and pay taxes. They contribute to the economy. To us, it’s a no-brainer. Everyone benefits.” So, in Oregon, a person in this

program can retain Medicaid coverage no matter how much she or he earns.

Even so, Gary Herron, 49, of Albany, Oregon, hopes to earn enough money through his new business to no longer need any disability benefits. A wildlife artist who created wood sculptures and paintings for 25 years, he had to stop sculpting because of weakness caused by MS.

Oregon's voc rehab provided him with a voice-activated computer and scanner to make prints of his paintings. He also received a grant to buy art supplies. Perhaps more valuable than the financial boost was the emotional one. Herron now has the interest and confidence to start working again, and he's currently trying to get a van with hand controls and a lift so he can drive to different sites to display his work. He's also writing a book on how to make wood sculptures, a book about living with MS, and his autobiography.

Meeting with a voc rehab counselor is the first step to determining how the service can help you. Some people need home modifications to be able to work. These could include wider doorways and a ramp for wheelchair access into and out of the home, a chair lift to get to a home office upstairs, even converting a tub into a roll-in shower so a wheelchair user can stay at home where the business is. In New York State, home modifications can be provided to homemakers with MS who don't do any other work, according to Lisa K. Roller, a coun-

selor for the program.

Other job-related needs might include personal attendant services, on-the-job training, help with reading or note-taking, and transportation to and from training programs. Most states also offer incentives to employers who hire people with disabilities.

Steve Shivers, the commissioner of Alabama's Department of Vocational Rehabilitation Services, believes his program is one of Alabama's best economic investments. "For every \$1 spent, \$20 will be returned to the state's economy through our clients' employment," he said.

The federal Vocational Rehabilitation Act of 1973 requires every state to offer such services. While not all programs are the same, you won't know the possible ways your state can help you unless you ask. Look in the governmental offices section of your phone book, or type your state's name and the words "vocational rehabilitation" into any search engine on the Internet.

Do it today!

***Tamar Asedo Sherman is a working reporter, thanks in part to help from VESID, the voc rehab service of New York State. She received driving lessons, hand controls for her van, and an architect drew home modification plans that included wider doorways, a roll-in shower, and a ramp connecting her garage to her house.***

# THE MAP STORE

## Our Map to Independence

by David Devoe

In November 1993, my wife, two-year-old daughter, and I were in New York, driving east along I-84 toward Hartford, Connecticut. It was midnight. We'd been on the road since early morning on our annual Thanksgiving pilgrimage from South Carolina to my parents' home in Maine.

We were all tired, but I was determined to make Hartford that night. I began having a hard time seeing. For the last hour of the trip I had to get my wife to help me read road signs.

And so began my journey with MS. Typically, it started as something seemingly minor. I thought it was temporary. We didn't even tell my parents during our visit. When we were home again, I sought medical attention.

"Optic neuritis caused by a viral infection," the doctor said. The symptoms slowly disappeared within a month. Two months later the optic neuritis returned. "You have MS. I

have referred you elsewhere," the doctor said, as he spun his stool around to walk out the door.

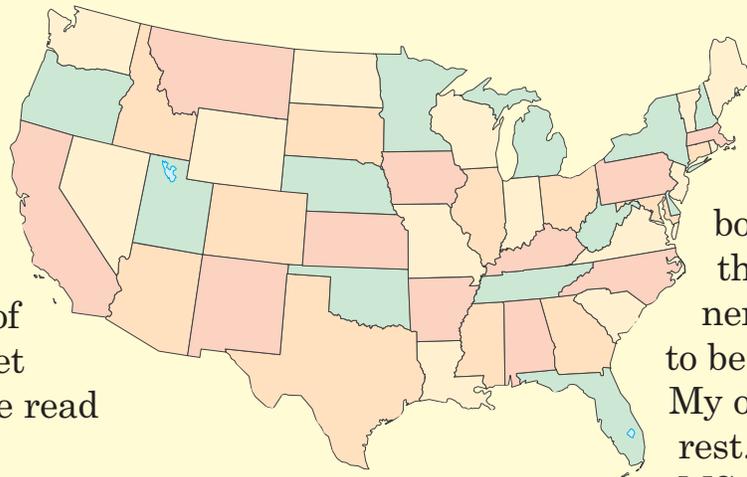
My reaction was a mixture of anger at this doctor with the bedside manner of a wrecking ball, and fear—a terrible sinking fear that I was going to die. My wife was pregnant with our second child; all I could think about was two young children growing up without a father.

Fortunately, we learned that I was thinking the absolute worst. My eyesight returned, this time with help from steroids. But over the next several months I dutifully reported every quiver, twitch, and gurgle of

my body to my neurologist. He cautioned me against focusing on every twinge of body noise. But as the family breadwinner I could not afford to be vulnerable again. My only plan was to rest. In my mind the MS could be managed,

if I just got enough rest at home.

My wife soon saw a different picture. She became an avid reader of MS literature and decided that we needed to prepare for the worst that might happen. Would she be able to provide for our family? Would our doorways be wide enough for a wheelchair? Worst of all, she was alone with her questions, since I did not want to hear about these possibili-



ties. Although I could walk and see and I appeared to function normally, she saw the real me who spent most of my time at home lying on the couch.

Seven months later our son was born, and with that tensions rose. My wife and I began to argue. As the months went by, our fights became pitched battles lasting well past midnight. They were followed by restless sleep and longer, harder days. I'd come home from work and collapse on the couch, wanting even less to participate with the family. We were beginning to spiral down that long dreadful path to the end of a marriage.

I thought she was trying to undermine my career. She thought I was in denial about my MS. At times my fatigue was so extreme my legs were wobbly. She wanted me to buy a cane. "But I don't need a cane ... I'm fine ... I just need rest," I argued.

And then something devastating happened. A close family member, the one who had what we thought was the perfect marriage, announced to the family that his marriage was over. A lightbulb went on in my head. "We're in trouble too," I said to myself.

I arranged for a week's leave, and we went on one of our favorite vacations: a family camping trip to the mountains. There we had long talks, and almost no fighting. There I agreed that we needed counseling. My wife had been asking for this for months.

It took us 18 months after my diagnosis to get to this point.

The following week, we were on our way to a counselor. From the very beginning, the counselor provided a safe environment for my wife and me to speak our minds. He played referee and threw out new starting points when things bogged down. During our weekly sessions, we would lay it all on the table, point fingers, accuse, and fuss. As a result, the fighting at home stopped. After nine months I understood that my wife was not trying to ruin my career, and she realized my concerns about providing for the family. Once our trust was regained, we began rebuilding.

I learned that we could not depend on me to be the family's sole supporter, but planning to leave a career that had taken me more than 14 years to build was hard to accept. I was an environmental geologist; I had earned college and graduate degrees; I had recently passed the final hurdle, the exams to earn a state license. I had acquired years of credentials. This was my dream job, but a lot of it was done at sites outdoors, involving long drives in all sorts of weather, and every day I was having greater and greater difficulty mustering the energy.

We decided that my wife would become the breadwinner. We did not want to put our children in day care, so we also decided that I would stay at home. We agreed that I needed to be productive. We looked at our options together.

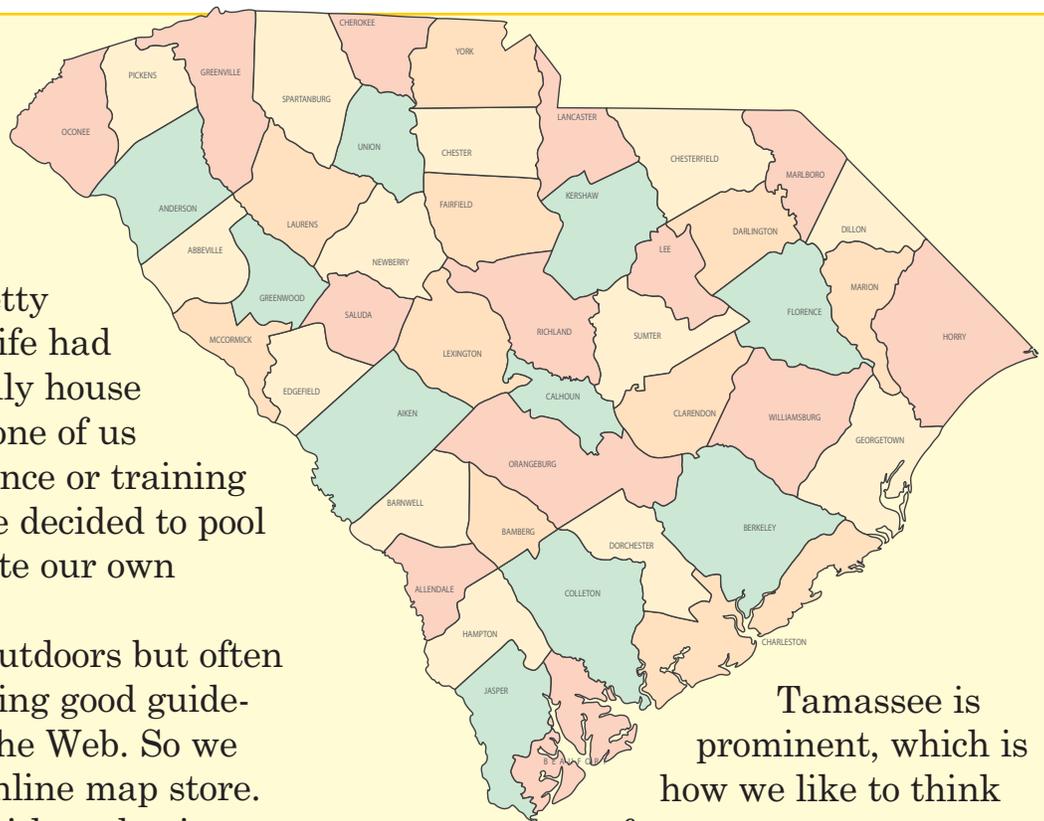
Counting me, my wife, and her dad

(who had recently retired), we had three master's degrees between us and two neighboring houses that were pretty much paid for (my wife had inherited an old family house from her mother). None of us had business experience or training in marketing. But we decided to pool our resources to create our own business.

We all loved the outdoors but often had a hard time finding good guidebooks and maps on the Web. So we decided to open an online map store.

In August 1997, with enthusiasm, a detailed business plan, and loans taken out on our houses, we jumped in. To minimize expenses I learned Web page design. We hired an e-commerce consultant only to assist in setting up the more difficult shopping cart and credit card connections. We attended conferences, obtained licenses, purchased computers, and established office/storage areas in one of our houses. And after six months of development time, we opened Tamassee.com Guidebook and Map Store [www.tamassee.com](http://www.tamassee.com). It now offers over 15,000 travel products.

The name Tamassee is Cherokee for "Place of the Sunlight of God". It is also a distinctive peak that juts out from the Blue Ridge escarpment in upstate South Carolina—and is visible from our backyard. Although it is not the highest peak in the area,



Tamassee is prominent, which is how we like to think of our company.

I am no longer an environmental geologist. I now own a growing bookstore. Our old house has stacks of books in the corners, computers in the dining room, and shipping/receiving in the living room.

None of our big fears have yet come to pass. I have had no reoccurrences of optic neuritis, and despite other symptoms ("wobbly legs", temporary double vision, and fatigue), I realize that things could be a lot worse. Perhaps managing my life has helped. Taking beta interferon for the past five years hasn't hurt either—except for the needle.

By redefining our lives I can now be "down" when MS insists and our world keeps on functioning. My role in the business involves our long-term projects, so I can be out for a day or more and not hurt our company.

We make a lot less money than we did before, and most of what we own is hocked, but our marriage is stronger than ever, our children are happy and well tended to, and every morning I wake up with a purpose. I think this is as good as it gets.

*David Devoe's interest in maps and hiking spurred creation of*

*the [www.tamasee.com](http://www.tamasee.com) Web site. Frank Guldner, his father-in-law, a retired army officer and college engineering instructor, combined his skills to develop store operations. David's wife, Frances, helped develop the store and now works elsewhere to ensure health benefits for the family.*

## Should You Tell Your Boss?

**Are you avoiding medical treatment to keep your health status secret on the job?**

yes  no

Some people obtain their MS care privately. That's not the same as **forgoing** treatment, which jeopardizes health.

**Are you telling lies or making excuses to cover MS symptoms more than once or twice a month?**

yes  no

Living in an atmosphere of deceit is socially isolating and emotionally draining.

**Have you received negative comments about your effectiveness on the job? A performance evaluation that was less than you expected?**

yes  no

Could these perceptions have anything to do with either your MS symptoms or difficulties you're having in your personal life because of this disease?

**Do you have episodes of staggering, slurring, or falling asleep at your desk?**

yes  no

Even if no one has commented to your face, peo-

ple may suspect you're drinking or using drugs.

Don't disclose yet! But any "yes" answer is a flag for action. Many people put off doing anything about job problems until they find themselves fired.

Consider having a confidential consultation with an occupational or physical therapist, a psychologist, a career counselor, and the intake staff at your state's vocational rehabilitation service. Call your Society chapter for referrals and info on any employment programs.

# THE SELF-EMPLOYMENT OPTION

by Cheryl Jewett



**S**o you want to start your own business? Giving birth to the concept—a product or service you want to sell—is just the tip of an iceberg. You’re contemplating an investment—of time, money, and hope—and there are common factors to consider, whether you want your business profits to be your primary income or your pocket money.

## Start with honest self-assessment

Managing a business isn’t for everyone. You need to be able to manage both people and money. You also need to understand what fuels you with excitement, because you should love what you plan to do. And you need to be realistic about your physical and emotional stamina.

Do you have backup in case of serious health problems? Even in the short term: let’s say it’s 3 p.m., your body has hit that proverbial wall, and you cannot go on one more minute (and you know what I mean). An angry customer is demanding your attention. Who covers for you?

I’m not trying to discourage you, but rather to encourage you to soul-search and brainstorm. Are you a self-starter, an organizer, a planner? If you are not, can you find someone to help you? What are your weaknesses and strengths?

## Get down to business with a business plan

If you’ve decided to go for it, you need a formal business plan. This is your company’s resume. The compo-

nents include your personal resume, a mission statement outlining the purpose of your business, and financial information. This should include a profit-and-loss statement based on your predictions of monthly income and expenses. You need to project the variables, such as part-time office help, bookkeeping services, warehouse and inventory, and the fixed expenses, such as rent, insurance, utilities and salaries. You need a balance sheet and a cash-flow analysis, plus a sensible projection of when you might reach your break-even point.

You also need the appropriate legal descriptions. Will your business be a sole proprietorship, a corporation, or a partnership? Is a copyright or patent needed? (The Web site for the U.S. Patent & Trademark Office is [www.uspto.gov](http://www.uspto.gov).) Is your location properly zoned for your type of business? Is a license required? Any potential lending institution will require all this information.

Your new best friends for developing your business plan could be your local chamber of commerce and your state vocational rehabilitation office. Look for them in the governmental offices section of your phone directory. Also try the Internet at [www.entrepreneur.com](http://www.entrepreneur.com).

The U.S. Small Business Association (SBA) site at [www.sba.gov](http://www.sba.gov) offers a wealth of information in amazingly non-bureaucratic language. Their toll-free number is **800-827-5722**. The Service Corps of

Retired Executives (SCORE) offers their invaluable help through their Web site, [www.score.org](http://www.score.org), or by phone at **800-634-0245**. SCORE gives free counseling plus low-cost workshops on numerous topics. The Small Business & Self-Employment Service (SBSES) is a free service of the Office of Disability Employment Policy of the U.S. Department of Labor which provides information, counseling, and referrals about self-employment and small business ownership opportunities for people with disabilities. SBSES, located at the Job Accommodation Network, is available through JAN's toll-free number 800-526-7234 (V) or 877-781-9403 (TTY). SBSES Web site: <http://www.jan.wvu.edu/sbses>.

## Financing

The greatest obstacle to business success has been identified as insufficient money. To favorably impress a lending institution (including your brother-in-law), you need to commit some of your own money up-front. Investing in your own business demonstrates how serious you are and ensures that you are less likely to walk away should things get rough.

Shop carefully for a loan, and don't be discouraged. The SBA experts will walk you through their pre-qualification for a loan guarantee program. And they'll connect you with local experts such as the Small Business Development Center.

I highly recommend starting your business small, and at home.

Consider leasing rather than purchasing the equipment you might need. It's far wiser to keep initial costs down, avoid drowning in debt, and focus your energy on growing your new business. For other suggestions on financing, check out magazines such as **Home Business** [www.homebusinessmag.com](http://www.homebusinessmag.com) and **Small Business Opportunities** [www.sbomag.com](http://www.sbomag.com) and visit [www.abilitiesfund.org](http://www.abilitiesfund.org).

## Sales and marketing

Marketing involves public relations, customer service, and advertising. Professionalism counts, so if you're new to this aspect of business you may want to outsource your marketing and advertising needs. No matter who develops your marketing plan, be sure you have good information on your customers' demographics and the best methods for reaching

### Should You Think About a Different Job?

1. Do you use any accommodations on the job such as flex hours, mobility aids, special parking place, a prearranged nap time?

yes  no

2. Are accommodations that worked well for you in the past not working now? Have you explored changing them? Are problems persisting anyway?

yes  no

3. Have you consulted specialists about your job problems? These include an occupational therapist, physical therapist, speech/lan-

guage specialist, career counselor, your state's vocational rehabilitation program—as well as people at the nearest Society office.

yes  no

4. Have you made adjustments, based on expert advice? Are problems persisting anyway?

yes  no

A "Yes" to Questions 2, 3, or 4, suggests it could be wise to think about asking to switch jobs, do part-time work, telecommute, or consider training for a more feasible occupation.

Discuss your options with your trusted advisors first—and take your time with the decision.

"No" to Question 1 is fine—unless you answered "Yes" to any questions in "Pop Quiz: Should You Tell Your Boss?"

Even if everything is fine at work, a good plan for retirement is a shrewd move. If you should leave work before age 62, you're likely to need a whole year's income in savings. According to the Social Security Web site, most applicants for Social Security Disability Insurance are not accepted on their first try. The rate of acceptance nationwide in 2000 was 46.7%.

them. Use the media outlets that your business can afford, since repetition of your message is almost surely needed to ensure success.

Familiarize yourself with your competitors so that you can differentiate your product or service from theirs. Think about what would encourage someone to switch to you for this product or service. Highlight this benefit in your sales pitch!

## Bookkeeping/taxes

Maintaining good business records is not only an absolute legal necessity, it enables you to monitor inventory, cash flow, tax-deductible expenses, and business growth. The U.S. Internal Revenue Service offers an excellent publication, #583 “Starting a Business and Keeping Records”. See [www.irs.gov/publications](http://www.irs.gov/publications) or call them at 800-829-3676.

To simplify things from the very beginning, start a separate bank account for your business. Get a ledger, an accounting journal, and business checks. There are several good programs for computerized bookkeeping, including Quicken, Peachtree, and Microsoft Excel. The SBA, SCORE, the public library, the Internet, and bookstores offer solid help on this topic.

If this sounds like more than you want to handle, you need to out-source. Hire accountant services from an individual or a firm that specializes in bookkeeping for small businesses. Ask for referrals from other small-business owners.

## Consequences of self-employment

The fear of losing hard-won Social Security income and health benefits



if MS rears up again can strike terror into your heart. To learn ways to safeguard your benefits, call your local Social Security office or their toll-free number: **800-772-1213**. If you choose to work and remain on disability, there **are** income limits. Be sure to find out what they are. Ask too about the “Extended Period of Eligibility” and continuation of Medicare coverage. WIPA (Work Incentive Planning and Assistance) can help you with benefits analysis. Contact [www.ssa.gov/work/ServiceProviders/WIPADirectory.html](http://www.ssa.gov/work/ServiceProviders/WIPADirectory.html).

A program called the Ticket to Work or Self-Sufficiency Program, is gradually being implemented state by state. Ask if it has come to your state yet. The Trial Work Period, or TWP, is already in effect everywhere, so for at least nine months, you can continue to receive all your Social Security benefits, no matter how high your earnings might be. Further, if you need to return to the disability rolls because of the same or related impairment within five years of leaving, there is no waiting period for the benefits to begin again. Social Security’s Web site, [www.socialsecurity.gov](http://www.socialsecurity.gov), has a marvelous comprehensive “Frequently Asked Questions” section.

There are lots of folks out there to help you. Listen well, learn all you can, and be absolutely positive that you have the resources to give your venture the best chance to work.

Then, plot your course, feeling confident and self-assured.

*Cheryl Jewett has worked in the employment services field for over 20 years, most recently for the state of Michigan. She lived with “probable MS” for years before being definitely diagnosed. She has written job search articles and taught employability skills to people with disabilities and many others.*

*She also “tiptoed into the world of entrepreneurship, offering employment services. But,” she writes, “my ongoing health problems kept me from plunging into self-employment. I chose not to borrow the money I would need. At one time, I might have seen living on SSDI as a negative, but now I accept where I am. I keep moving with whatever’s needed to enable me—canes, crutches, a walker, a manual wheelchair, or an electric wheelchair—and I’ve learned adaptation, humor, and flexibility.”*

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience, and expert opinion, but do not represent individual therapeutic recommendations or prescription. For specific information and advice, consult your personal physician.

# DISCLOSURE OR NOT?

by Katherine Shaw

“I have MS and I didn’t tell anybody,” President Josiah Bartlet announced in the season finale of NBC’s “The West Wing”. For this,

had he disclosed his MS, he wouldn’t have been elected in the first place.

Of course this is TV, but the issues are very real. Many individuals with MS don’t have the option of not disclosing, but for those who do, the choice is a difficult one because it involves significant risk. There are personal and professional issues. There are issues of privacy, trust, and integrity.

From a career standpoint, disclosure may mean the fast train **off** the fast track. If you disclose to only a select few, someone might slip up and leak information unintentionally. But if you don’t disclose and you have a bad day at work, maybe slurring words or losing your balance, alcohol and drugs could be suspected, even if your overall job performance hasn’t been affected. Further, if a person who needs an accommodation waits too long, an employer may already have seen productivity decline. This poisons the climate for obtaining accommodations that work.

For Cheryl Woods, a 43-year-old nurse in Houston, Texas, the choice to disclose her MS was a nightmare. In 2000, she was fired after openly discussing her diagnosis. “It was a devastating situation,” she recalled. “I had four glowing evaluations. The one following the disclosure of my diagnosis was horrible.” Woods proceeded to write a rebuttal to this last

Bartlet, the fictional U.S. President played by actor Martin Sheen, is facing a flood of questions. His attorney is concerned that the President—and the family members, aides, and advisors who knew—will be charged with fraud. The friends and staffers who didn’t know are feeling misled and uncertain. The President’s ability to be reelected is in question, and a confidential survey indicates that

evaluation, and was subsequently asked to resign. Her attorney advised her not to quit, or she wouldn't have a case. So she began keeping a daily journal of the events that eventually led to her being fired. Woods has now filed suit under the ADA, but points out, "taking the matter up in court is time consuming, expensive, and stressful."

She was open about her MS when she started searching for a new position. "The HR person at one hospital explained that she didn't have a problem with my MS. She was very positive and told me she'd check my references, but I never heard back."

Woods was promptly hired at the next hospital she tried. "I'm paid \$10,000 less than I was at my previous position, but I needed the job," she said. The hiring procedure involved her undergoing a physical exam and providing a list of all her medications. She listed Avonex and discussed with the nurse practitioner that she intended to keep her condition private. She was told that the information would not leave the office. So far it hasn't.

To protect her privacy, Woods has decided not to use her cane until her 90-day probationary period is over. She also has a handicap-parking sticker that she's not using, and she's trying to decide if she'll use it later. "It's hard to keep a secret, especially since I think there are people who are suspicious," Woods



said. "There are days when I've had to park at the back of the lot and I'm on my feet all day. When I get home, I'm physically exhausted. Still, I would advise people not to tell if they don't have to tell."

According to Deborah Miller, PhD, LISW, director of Comprehensive Care at the Mellon MS Center, Cleveland Clinical Foundation, "There's no legal obligation to discuss a medical condition with a potential employer. However, it is important to describe any special accommodations that are required or conditions that affect job performance. It is also essential that accurate information be disclosed on health insurance review forms."

Miller also points out that it is very important that people make adaptive changes if necessary.

Otherwise the result may be an on-the-job injury that is not the fault of the employer—and that could result in a disputed workers' compensation claim.

For Aiden McKenna of New Orleans, disclosure was not an option. Now 44, McKenna was diagnosed with relapsing-remitting MS in 1982. Following an exacerbation in 1990, he began using an electric scooter. After a 12-year career with the federal government, McKenna began law school in 1990, passing the bar in 1994.

Following law school, one of McKenna's professors hired him as an assistant district attorney. "He knew when he hired me that I was in a chair," McKenna said. "I wanted to be as up-front as possible, so I told him that I didn't know if I could handle a full day." As a result, his boss made arrangements for him to be on a flex-time schedule.

McKenna described three types of reactions to MS that he's experienced in the workplace. There are those who don't care at all. There are those who try to learn and deal with it. And there are those who care too

much. The latter group, while certainly thoughtful, can go too far in terms of coddling.

"They are so overprotective that they keep you from opportunities," explained McKenna. "They're concerned. They don't want to overburden you, so they don't offer you the opportunity for a new project or a promotion. It's better if the individual is offered the opportunity and

then allowed to make the decision.

"I'm extremely fortunate," continued McKenna. "We have unlimited sick days here, but it's a badge of honor that I've only used eight!"

Sally Unger, a 36-year-old advertising executive from Boston, has had relatively benign MS since she was 25. She has a slight limp and stiff legs after she's been sitting in a chair for a period of time.

"After a two-hour meeting, I'm a bit shaky when I first get up," Unger said. "When my coworkers ask about my limp, I tell them I have a bad back."

She is happy with her decision, but she's not worry-free. While her company has several hundred



employees, minor health insurance claims are administered through the company's benefits department. "I'm never quite sure who knows what," Unger said. "If our benefits coordinator talks to my supervisor, I could easily be found out."

Unger is careful about her insurance claims. "My doctors have been great about stating my symptoms, such as urgency or UTIs, rather than stating the MS diagnosis," she explained. "I know if someone did some digging, it wouldn't be hard to trace because of my MRIs, but I figure the less my file stands out, the better."

"There isn't any black-and-white advice on the disclosure issue," observed the Mellon Center's Deborah Miller. "I am aware of situations where employees have been dismissed within two months of revealing a diagnosis (never, according to the employer, for MS-related reasons), and I've seen situations where employers have shown enormous sensitivity in making special accommodations. To the extent that an employee can show he/she is

valuable and wants to keep working, employers are often fair and reasonable.

"It's more important to stay employed than it is to do the same job you've always done," Miller concluded. "The benefits of work are multidimensional, including the community aspects, physical functioning, and the need to protect future Social Security and disability benefits."

While the ADA does provide some protection, it does not eliminate discrimination and ignorance. Thorough planning is key to making a sound disclosure decision. It is not a decision to be made alone, or immediately after diagnosis when one is under severe emotional stress. Friends, family, social workers—as well as the National MS Society—are all valuable resources in planning an effective disclosure strategy.

*The author writes under the name Katherine Shaw to avoid public disclosure of her MS. She has been living and working with MS for 11 years.*

The Society produces many online programs on employment and MS symptoms. Log on to [nationalmssociety.org](http://nationalmssociety.org), click on "Living with MS", then "Webcasts and Conferences", then "MS Learn Online" for the following Web casts:

- Symptom Management/Staying Well: Cognitive Dysfunction
- Symptom Management/Staying Well: Fatigue
- Life Planning and Independence: Understanding Your Employment Rights

Many links to resources for employment and disability rights are also available by logging on to [nationalmssociety.org/employment.asp](http://nationalmssociety.org/employment.asp).

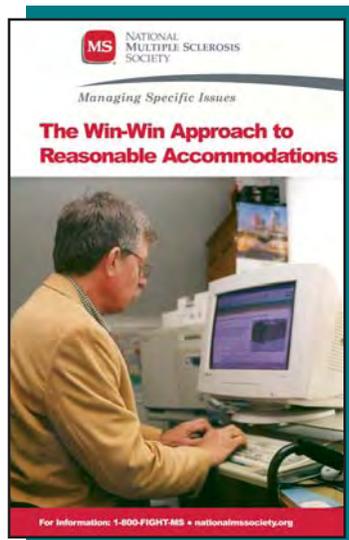
# MAXIMIZE YOUR OPTIONS

by Beverly Noyes, PhD, LPC

## An overview from the National MS Society

Some jobs are compromised by MS symptoms much more quickly or directly than others. If your job is very physical, you'll be concerned about fatigue, balance, or problems walking. If your job requires planning and problem-solving, you will be more concerned about subtle cognitive changes—problems with thinking, memory, or concentration. Fatigue and cognitive problems, which trigger more unemployment than mobility impairments do, can be hard to accept personally, but they are not automatic bars to holding a job.

The most important point to keep in mind is your personal decision to



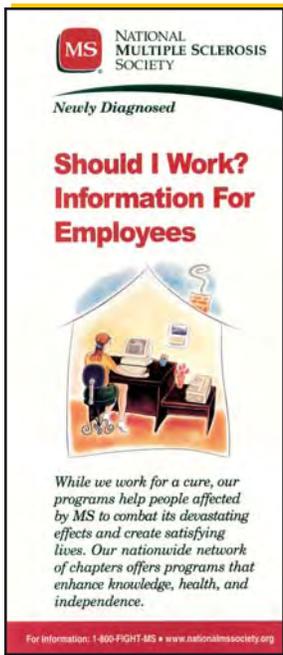
keep working. The keys will be flexibility and creativity to make adaptations in the way you do your job, and your willingness to seek accommodations available to you through the Americans with Disabilities Act, or ADA. Equally vital in some situations will be your willingness to consider changing the type of work you do and taking on the challenge of training or education for the change.

## Identify ways to manage your stress

While research has not been able to identify any causal link between stress and either the onset or the worsening of MS, coping with any unpredictable chronic illness while managing the demands of work is bound to be stressful. We think the reasonable approach to this is to review your stress management techniques. If the things you used to do to escape pressure and tensions no longer provide relaxation or enjoyment, you need to explore new options. Swimming, water aerobics, meditation, yoga, or tai chi have all been cited as helpful by other people with MS. You may benefit from the advice of a counselor or recreation therapist.

## Plan for the future

Americans commonly change careers; some people do so several times in their working life. If your current job could be compromised by a worsening of your symptoms, start thinking



about your next career move. A vocational rehabilitation specialist or career counselor can help. Make sure you understand the sick leave and disability benefits provided by your current employer, and investigate any retraining or continuing education your employer offers.

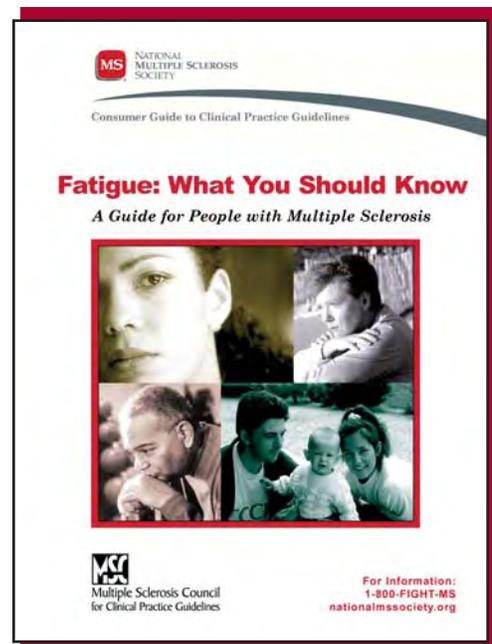
There is no need to go it alone. The Society office nearest you may have the referrals you need, or a job retention program, or peer counseling.

The office will certainly have Society publications. These include:

- Information for Employers
- Should I Work? Information for Employees
- What Is MS?
- Taming Stress in Multiple Sclerosis
- ADA and People with MS
- “But You Look So Good”—Coping with invisible MS symptoms
- Fatigue: What You Should Know
- The Win-Win Approach to Reasonable Accommodations

Call **1-800-344-4867**. We want to help you maximize your employment options.

*Beverly Noyes is the Associate Vice President of Programs and Staff Development at the National MS Society. Previously at the Society’s National Capital Chapter in Washington, DC, Dr. Noyes managed Operation Job Match, a pioneering employment program for people with MS and other adult-onset disabilities. Dr. Noyes is a certified career counselor and a licensed professional counselor.*



**Additional Resource:** Office of Disability Employment Policy, U.S. Dept. of Labor, Frances Perkins Bldg., 200 Constitution Ave. N.W., Washington, DC 20210. Tel: 866-633-7365. TTY: 877-889-5627. Web site: [www.dol.gov/odep/welcome.html](http://www.dol.gov/odep/welcome.html)



**The National Multiple Sclerosis Society  
is dedicated to ending the devastating  
effects of multiple sclerosis.**



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