FOCUS ON EMPLOYMENT

How to stay in the game

A Special Reprint

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(Illustrations by William Stanton
and Travis Stanton.)
The numbness always is there, in my feet and hands. Often I wiggle my fingers and toes to make sure the blood is circulating so I know that when I get up, I will be able to walk, or when I take a pen or open a laptop, I will be ready to write or type.

I’m in the middle of a business meeting. Suddenly, the numbness spreads, up the legs, through the arms, quickly enveloping my face. No one in the room knows what is happening just below my skin. If I am fortunate to keep a poker face and not slur any words, my secret will continue to be safe. No one can tell that a surge in my MS symptoms is underway.

BY KENNETH BANDLER
Uncertainty unlimited
How long this numbness will persist also is impossible to predict. Will it be an hour this time, or the rest of the day? Does it signal the beginning of a real exacerbation, continuing for several days, or maybe a week or longer? It is only 10:00 a.m., and I need to be creative and responsive.

The majority of people with MS do not exhibit distinct signs of the disease. “You look much better than you should,” my neurologist declared when he confirmed in May 2003 that the long dormant disease had advanced.

How to manage fatigue—an MS symptom as unpredictable as exacerbations—and stress—a factor that can impact adversely on MS—are continual, emotionally draining challenges, especially when one is determined to sustain secrecy while striving to perform well at work and maintain an active family life.

Do I tell or not?
Only a few in my family knew about my MS. I was hesitant, fearing the reactions of colleagues and friends. Besides, I believed my condition would change for the better, so why go public?

That illusion evaporated when my doctor reminded me that currently there is no cure for MS, that the interferon I self-inject is used to contain its progression. How I feel today would likely continue indefinitely.

I continued to work hard as the public relations director for a national advocacy organization—not a stress-free job. All would be fine as long as I found ways to keep pace.

When my boss asked why I suddenly was seeing doctors so regularly, I told him there was nothing to worry about, that whatever I have is not life threatening, which was true. But to avoid further questions, I decided to not tell anyone at work again when I was seeing a doctor, and I tried to schedule appointments during lunch time.

Yet, increasingly, I realized that I would need to tell my boss. Telling at least would ease the emotionally taxing debate in my head. But when would be the right time?

Long talks with family and with staff at my MS center in New York convinced me that telling would be personally salutary. I was reassured that since I had been in my position for more than five years, my record would speak for itself—and would outweigh any doubts about my ability to continue.

But who really knew? Could I trust the advice? In the end, it came down to one person’s decision. Could I even trust my own judgment?

When do I tell?
There never was a right moment. Several times I thought I was ready, but pulled back, worried about negative reactions. As I passed the first anniversary of starting on interferon, I decided I could wait no longer. On a Friday evening, when the busy workweek had quieted down, I shared my situation with my boss.

My health is normally a private matter, I explained, but something had
changed in the past year that needed to be shared with him. Recalling our conversation seven months earlier about my frequent visits to doctors, when I stated that what I have is not life threatening, I reaffirmed that was true. What I have is MS, I’ve had it a long time, but since there has been a change in my condition and the disease is totally unpredictable, I wanted him to know.

The immediate reaction was shock—and concern. “I always wondered what your secret elixir is,” said my boss, who, like many, had seen only a healthy and energetic colleague. Since he knew little about MS, we continued the conversation. I explained MS, my experience dealing with it, and the uncertainty that lies ahead.

“Will you be compelled to resign?” he asked, and I replied, “Of course not.”

I left him with weekend reading, an article I had written about the loneliness of coping with MS. I wrote it several months earlier, initially as a form of therapy, but I had become eager to publish it—indeed, the few who knew about my MS were encouraging me to do so. A few weeks after our conversation, the article was published in the *International Herald Tribune*, which actually made it easier to tell others.

Almost as quickly as an exacerbation could hit, news of my MS permeated my place of employment and beyond. It yielded many calls and e-mails of empathy and admiration. But understandably, only a small percentage of my colleagues came forward to say something. It certainly is not easy to figure out what to say to someone you know who is dealing with a disease.

**And now?**

Since going public, conversations at work have showed no indications that those attitudes of empathy have changed. Months later, work is the same. I work. I travel. I attend and run meetings.

Adjustments persist, given the uncertainty of the disease. Are there difficult days? Sure. What is essential is conveying honestly that the work can be done. When an opportunity came up for an overseas business trip, my boss questioned, out of concern, whether I should go. Without hesitation I said I’d tell him when I’m not able to travel.

Significantly, the burden I carried for so long, struggling whether to tell or not, is gone. If I need to take a break, I can comfortably say why. When something developed suddenly that required taking a day off to meet with doctors, there was understanding.

True, each person with MS must evaluate his or her own personal employment circumstances. But, as I learned, we need not necessarily fear telling others. Agonizing over whether to tell or not definitely creates more unneeded tension and stress—a thing we people with MS do not need.

Kenneth Bandler is director of communications for the American Jewish Committee. A longer story about his experiences, “Office Secrets: After Diagnosis, A New Dilemma” by Amy Dockser Marcus, was published last spring in *The Wall Street Journal*.
A good-looking man rolled to the stop sign as I rounded the corner on my scooter. He greeted me; I guess I looked bewildered. “You were my grade school counselor,” he said. I was pleased; I wondered which child he had been.

I had worked as a counselor at the Mendocino Grammar School in 1995 as an intern. I enjoyed great success with the children and had a good relationship with my peers. There was a job opening for a school psychologist for the following year. I applied;
I thought I was a shoo-in. My résumé was impressive and I had been doing the job for a year. I waited eagerly to hear when my interview would be. Three days before school started, I received a call from the principal saying someone else had been hired. I was never even offered an interview. I wanted that job!

According to the Americans with Disabilities Act (ADA), all pre-offer inquiries about an individual’s diagnosis or possible future disability are prohibited. Interviewers can ask about current abilities required by the job. However, I had readily disclosed; everyone knew I had MS. It was no big deal. Or so I thought. Had I been more savvy, I might have thought I was being discriminated against.

Instead, I decided to move on.

**Does disclosure hurt?**

Pamela Hirshberg, programs manager at the National MS Society’s Southern California Chapter, advises her clients that it might. She strongly urges people to think through how their peers and supervisors might react and to practice what they will ask for with an employment counselor or advisor.

“In my employment groups, I tell people not to disclose unless they need a specific accommodation,” Hirshberg said. “Even then, they don’t need to tell their diagnosis. They need to explain how an accommodation will solve problems caused by a medical condition,” she said.

**Does ADA protect us?**

According to ADA attorney Charles Goldman, who practices in Washington, D.C., enforcement issues are rarely clear-cut. ADA provisions are a continuing process … open to interpretation. Employers who disobey the law can be cited for non-compliance. But most never go to litigation according to Pamela Hirshberg.

“To go to litigation an employer would have to say you were refused a job, or terminated, or not promoted because you have MS. Employers are too smart to do that nowadays,” she said. There are many more subtle ways for employers to discriminate.

The best, most specialized attorneys may know all the fine points. If you decide to make a formal complaint, it is also very important to have your neurologist on board. You may be called on to provide professional medical opinion about whether you can do a specific job.

Clearly fighting employment discrimination in court is difficult, expensive, time-consuming, and emotionally draining. But ADA does offer us some protection because it has helped change public attitudes.
Some background

I first heard the phrase “reasonable accommodation” years before it became the cornerstone of the ADA. It appeared in the Rehabilitation Act of 1973, which covered federal employees, and it heralded a change toward people with disabilities. Some very progressive private employers adopted policies of this act long before ADA made them legally obligated to do so.

The ADA was passed by Congress in 1990. It was the first comprehensive legislation passed by any country to prohibit discrimination on the basis of disability. It covers all aspects of the employment relationship, from recruitment to firing, and it goes well beyond those issues to provide protections in public facilities, including transportation, telephones, and more.

Historically, ADA is an extension of the Civil Rights Act of 1964, guaranteeing full participation in American society for all people with disabilities, just as the Civil Rights Act guaranteed this for all people regardless of their race, sex, national origin, or religion.

The landscape for people with disabilities has changed dramatically in the years since. Before that time it was unusual to see disabled people who were working. Today, attitudinal barriers continue to break down as more people with disabilities become employed. Moreover, employers are aware that there are guidelines as to what constitutes discrimination.

What to do if you experience disability discrimination

Contact your National MS Society’s nearest office first. In addition to information and advice on negotiating with your employer, your chapter may be able to refer you to a professional mediator. If, ultimately, you want to file a legal charge, shop around for a lawyer. Don’t assume that the person who did your real estate closing knows the ADA. Call your state or local bar association and ask for someone who is experienced in employment law. Ask if he or she represents management or employees. Don’t be afraid to ask the dirty question, “What are your fees?”—J.D.
How ADA redefined disability
ADA covers almost everyone with MS. It doesn’t apply only to those in wheelchairs. It covers every person with an impairment that “substantially limits one or more major life activities.” Invisible symptoms like MS fatigue or bladder dysfunction clearly fit this definition. Initially, people thought about ADA making workplaces wheelchair accessible. They weren’t thinking about people with MS who might require an adjusted schedule because of issues of stamina. But an adjusted schedule can be a reasonable accommodation based on the “must do” functions of a job.

Suppose you are a toll taker on a freeway and MS fatigue leaves you too tired to get to work. You can’t expect the highway department to keep you on. (You could ask for a different type of job.) But if you were an accountant for the highway department, you might say, “Let’s adjust my schedule.” A vacant desk and a vacant tollbooth are two different stories. Adjusting an accountant’s schedule could be considered a reasonable accommodation, according to attorney Charles Goldman.

Today individuals with disabilities are far more likely to be contributing their abilities and their intellects to their communities. And the world gets something back.

Did ADA work for me?
By 1990 my function was noticeably declining. I struggled more and more with fatigue and with pain. I have an MA in Art History and was working as an art critic. I could no longer climb stairs or do the hustling necessary for my job. I agonized about what I should do. With the help of my therapist, I decided to study psychology and become a psychotherapist. A friend told me that California’s Department of Rehabilitation (DOR) would help people who needed to make career changes for health reasons, so I contacted them.

My DOR counselor was a wonderful man named Stan White. He worked with me for some time and had me attend workshops with other excellent counselors. With their help I entered a graduate program and received my MA in Clinical Psychology in 1993. The DOR helped pay my tuition and subsidized books and school supplies.

But then my career plans derailed. My marriage ended. I was on my own. And my MS was progressing. I had to move to a rural community, and there I had to develop my own counseling internships. I ended up working with many different populations—from children to alcohol...
and drug addicts. In all my internships, reasonable accommodations were made for me without questions. I was granted flexible work hours. The DOR purchased an adapted van to carry me and my scooter. Driving instruction was provided. Occupational therapists (OTs) designed plans to minimize my fatigue and maximize my function. It was done with great sensitivity. My life was on a roll.

Then came “The Driving Evaluation.” Here I got into some murky territory. The driving test was scheduled over a three-day period. It was grueling. I might compare it to an able-bodied person having to climb a wall as part of a driving test. On the final day I was not allowed to drive when my energy was at its peak. The same OT who had taught me to minimize the impact of my fatigue by scheduling tasks for my best times, now insisted that I do several extra transfers, and take the test after I was totally exhausted. I did not pass.

I appealed and was granted a new evaluation, but it had to be done in a distant city, where the three-day exam would be compressed into a single day. I tried to argue, but the OT insisted that they needed to see me “at my worst.”

Ultimately, I was advised to close my file with the DOR. The hand controls would be removed from the van and I would no longer be able to drive. I had no other options, so, reluctantly, I took their advice. I am still processing this loss.

Since that time I have been self-employed conducting therapy groups in my home. This works well. There is much work to be done. With my background, I feel well qualified to be part of whatever comes next.

Where we all are now
Despite ongoing problems, the world is very different from what it was before the ADA. Today individuals with disabilities are far more likely to be contributing their abilities and their intellects to their communities. And the world gets something back. Not to sound like a Pollyanna, but as a therapist, my MS has given me insights into the human spirit I couldn’t have imagined before dealing with this disease. Of course, if they found a cure tomorrow, I would take it. After all, I’d still have the insights.

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Joanne Dickson is a freelance writer and a therapist in Mendocino, California.
Employment

On the Job with Fatigue and Cognitive Issues

BY JO STRATMOEN

Fatigue and cognitive issues—not physical disability—are the major reasons why many people with MS eventually leave the workforce. Up to 87% of people with MS report significant fatigue. Cognitive dysfunction affects 45%–65% of people with MS. Fatigue can increase cognitive problems. So can stress. If not addressed, they may combine into a downward spiral.

Strike one: fatigue
If you have MS, you probably know what dragging yourself out of bed to get to work feels like. But, Susan Forwell, PhD, an occupational therapist with the School of Rehabilitation Sciences at the University of British Columbia in Canada, echoes most
experts when she says the causes of fatigue in MS are poorly understood.

“Some researchers believe fatigue is a direct consequence of the disease process while others suggest that it is also a factor associated with mobility problems, depression, and sleep disturbances,” Forwell said. Moreover, research is hobbled because there are no truly objective measures of fatigue. It is hard to tease out the factors that go into a person’s perceptions of his/her fatigue—and just as difficult to verify the outcomes of treatment.

“The more tired I get, the more stressed I get and the more I find it hard to concentrate and the more tired and stressed I get. It’s a vicious circle.”

Cytokines and axons: connections not proved
One mechanism of the disease process is the elevation of pro-inflammatory proteins called cytokines. In experiments, these cytokines trigger fatigue and sleepiness. Another mechanism is a loss of axons, the nerve fibers that conduct impulses through the central nervous system. Axon loss is associated with higher levels of disability. But, so far researchers have not been able to show that either elevated levels of pro-inflammatory cytokines or higher degrees of disability are always connected to higher levels of fatigue in MS.

Problems with mobility, sleep, or depression
Having any mobility problem increases fatigue. People with disabilities spend a lot of energy negotiating daily tasks. Depression shares some common attributes with fatigue, such as lack of energy and decreased motivation. “And sleep problems result in some of the same symptoms,” Forwell said.

But once again, researchers cannot be certain that depression or sleep problems correlate strongly with the level of fatigue.

What to do
Clearly, getting a handle on fatigue is an ongoing process. Each person has to uncover the strategies that help her or him. Moreover, the degree to which a person can manage fatigue in the workplace depends on the type of work the individual does.

“What those who work in offices have a better chance of being able to reconfigure their workspace and workload to accommodate their fatigue,” Forwell said. “Avoiding stairs, taking regular breaks, and having a comfortable place to rest from time to time can help a lot.”

Energy conservation techniques, shown in the table on page 12, may be essential. Maintaining physical fitness also decreases fatigue so an exercise program is equally important.

“What unfortunately, some jobs require people to be on their feet all day. They
cannot practice energy conservation,” Forwell noted. “I advise them to try and switch to a job within the same industry that allows them to sit and take regular breaks.”

First seek medical help
Check with your doctor if you habitually start the day feeling unrested or have symptoms of depression. Ask if any of your medications could be contributing to your fatigue. Ask about any herbs or dietary supplements you use as well, because some of them increase fatigue.

Then seek therapists who specialize in job retention
An occupational therapist can help develop strategies for performing daily activities at work and at home.

A vocational rehabilitation specialist can offer solutions such as redesigning a workspace or identifying other more suitable jobs. The Rehabilitation Services Administration, a federal agency, supports vocational rehabilitation programs in every state. Services may include funding for training, home or workplace modifications, and assistive technology to help people with disabilities obtain or maintain work. To contact your state’s vocational rehabilitation program, go to www.jan.wvu.edu/sbses/vocrehab.htm or telephone 800-526-7234 toll-free.

Do medications help?
This is a controversial area as no one medication clearly works well for everyone. According to Dr. Forwell, modafinil (Provigil®) is the most useful agent available at the moment. This conclusion has come under scrutiny, as indicated in the box on page 15. Amantadine (Symmetrel®) has demonstrated a modest benefit on MS fatigue and is much less expensive than modafinil. Both fluoxetine (Prozac®) and bupropion (Wellbutrin®) may be helpful.

Strike two: cognitive problems
You’re at your desk working on a spreadsheet program and someone stops by to talk about last night’s baseball game. This brief interruption is enough...
to derail your entire train of thought. You have to go back and start again. The impact of MS on cognition can make the simplest task into a complicated mental hurdle.

According to neuropsychologist Lauren Caruso, PhD, people with MS exhibit varying degrees and types of cognitive problems depending on where lesions are seen in their brains and whether atrophy, or loss of volume in the brain, has occurred. Magnetic resonance imaging (MRI) studies have helped clarify why many people with MS experience cognitive dysfunction.

“The most common problems to affect performance on the job are problems with attention, concentration, and short-term memory,” Dr. Caruso said. It may become difficult to concentrate on two things at once. The ability to multi-task or think on your feet may diminish. Prioritizing thoughts, moving smoothly from topic to topic, or controlling the expression of emotions may become impaired.

In addition, some cognitive problems affect vision or communication. Dr. Caruso noted, “It is sometimes difficult for people with MS to recognize the relationship between objects that they see, or to find the right word to express what they want to say.”

While these are correctly called cognitive problems, they don’t affect intellectual function. Most people with MS are able to reason, learn, draw from their knowledge and experiences, and make appropriate conclusions and judgments.

**What to do**

General tips for cognitive issues are listed below. These ideas may also help:

For better concentration, ask to have a private office or a workstation separated from the rest of the gang.

**Cognitive strategies**

- Write everything down: diaries, loose-leaf organizers, and hand-held computer/organizers are helpful.
- Have a particular place for everything and always put things back where they belong; encourage others to do the same.
- Repeat things that need to be remembered. And write them down.
- Try not to get hung up on recalling a word. People are often happy to chime in with the right one. Let them.
- Take your time. Plan your work and don’t be rushed by anyone.
- If you find cognitive problems crop up at a particular time of day, reorganize activities so you have the more demanding things done before that time.
When working on a complicated task, switch the phone to voicemail and turn down the volume on the computer to limit interruptions or disturbances.

Avoid situations where quick mental processing is required. Help your employers and colleagues to understand that you might not think as quickly as you used to but this doesn’t mean that you can’t think effectively when given time.

Work on being well organized. According to Dr. Caruso, this can go a long way to dealing with cognitive problems in the workplace.

Get adequate sleep. “Cultivating regular sleep patterns is one of the most important things to do to moderate cognitive problems,” Dr. Caruso believes.

Professional help can make a difference. Neuropsychologists are experts in evaluating cognitive problems and developing compensating strategies for them. Occupational therapists and speech/language pathologists also have expertise in cognitive problems. Your MS health professional or Society chapter can provide referrals.

Alternatives?
People try a variety of complementary therapies to alleviate cognitive problems or to address side issues, such as stress, that make the problems more intense. Discuss any herbal or dietary supplement or other alternative treatment such as acupuncture with your MS health professional first. You should expect your MS professional to listen to your ideas and give you valuable insights. Practices such as yoga and meditation are known to help many people.

You’re still in the game
While fatigue and cognitive problems caused by MS can have a major impact on the ability to work, every individual is different. Explore what works for you in order to learn what accommodations could contribute to your personal job performance. Look for strategies that compensate for your particular problems.

Keeping your job may feel like a full-

Two ways to protect your future

One: Act early to protect your job if you know you are developing cognitive problems. Carefully prepared disclosure may be in your best interest. People with hidden cognitive problems may end up fired—and people who are fired are not eligible for unemployment benefits or disability insurance coverage.

Two: Be aware that flexible schedules are not the same as reduced work hours. Flextime should add up to a full work week. If you opt for part-time work and retire altogether at a later date, your disability benefits will probably reflect your most recent earnings. Be very sure you know how your benefits would be affected should you reduce your hours or accept a lower paying, less stressful job. Have a candid conversation with your benefits manager before telling your employer what you plan to do.
time job in itself. Only you can know if the effort continues to be worth the result. You should know that many people with MS continue to work for many years, thanks to their determination, some good luck, and the help of knowledgeable professionals.


**References for your health-care professional**


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**Mixed messages about Provigil® for MS fatigue**

Provigil has been used to treat excessive sleepiness caused by certain sleep disorders since 1999. In 2000, the manufacturer, Cephalon, conducted a study to evaluate its effect on fatigue in MS. The findings stated that people taking Provigil reported less fatigue compared to people taking a placebo. Two small, subsequent studies reported similar findings.

Physicians began prescribing Provigil, off-label, for MS fatigue. Since there were no serious side effects, it seemed safe to give it a try. However, a rigorous controlled trial in 115 people with MS, published in the April 2005 issue of *Neurology*, concluded that there was no improvement of fatigue in people treated with Provigil compared to people taking an inactive placebo.

The investigators suggest that “placebo effects” may have contributed to the positive results of earlier studies. But many respected clinicians who treat people with MS, including several who reviewed this article, are impressed with the positive effects of Provigil on MS fatigue. They are mainly dismayed by its high cost. The researchers acknowledge that further studies are needed before firm conclusions can be made about this drug.

—Rochelle Kraut

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Provigil® is a registered trademark of Cephalon, Inc. Prozac® is a registered trademark of Eli Lilly and Co. Symmetrel® is a registered trademark of Endo Pharmaceuticals. Wellbutrin® is a registered trademark of GlaxoSmith Kline.
Hearing Denise Veazey, Linda Tucker, and Karen Jackson describe their schedules is exhausting—no matter how much of a capable, Type A person you might consider yourself.

“I’m up at 6:00 AM,” Veazey said, “and I’m on the go until 8:00 PM.” When she’s not on the phone with her customers at Mary Kay Cosmetics, she’s working on her first novel, getting her essential hours of exercise, or helping organize Women Against MS events with the Society’s Mid South Chapter—all from her wheelchair.
Linda Tucker’s work also has her on the phone for much of the day, talking to people all over Tennessee about long-term care insurance. “I’m a living, breathing example of why that’s important,” she said. The slow progressive course of Tucker’s MS has left her quadriplegic.

Karen Jackson works five days a week for a surgeon. Three days she’s at the office in Washington, DC, answering calls and consulting with the doctor; two days she’s at home in Fort Washington, Maryland, where she can work as her MS fatigue allows.

While all three of these women are special, they’re far from unique. People with disabilities—including many with MS—are finding ways to keep working, or start working again, by telecommuting, or doing “telework.” Technology, whether it’s the Internet or an old-fashioned telephone, helps create the most accessible office of all.

A “reasonable accommodation”
Telecommuting is recognized as a possible “reasonable accommodation” under the Americans with Disabilities Act (ADA). The federal government encourages it for people with disabilities, most recently through its “New Freedom Initiative.” Still, getting started isn’t as simple as it sounds.

What is often most successful is persuading your current employer to offer a schedule like the one Karen Jackson has: part on site, part from home.

“Most employers will allow a person to work at home at least one day a week—especially if the person has already demonstrated themselves as a valued employee,” said Steve Nissen, director of Operation Job Match at the Society’s National Capital Chapter.

Nissen, who directed a special telework initiative from 1997–2002, has found that some fields are more conducive to working from home than others: “Web design, computer programming, college and university counseling, writing, editing, and even teaching at the college level, where the prep work can be done at home, are all acceptable choices.”
“We’re moving rapidly toward a more flexible workplace for all employees,” said Jane Anderson of the Midwest Institute for Telecommuting Education (MITE) in Minneapolis, Minnesota.

**The bridge to the right job**

Operation Job Match and MITE both work with employers to help create placement options. For example, Nissen found work for former floor nurses, whose MS-related fatigue made those jobs impossible, with hospitals that needed help processing radiology reports. Anderson’s agency worked with the United Way of Minnesota to develop its “First Call for Help” hotline. All calls are answered by people with disabilities from their own homes.

For Linda Tucker, a former girls’ basketball and softball coach, the bridge was Jeanne Brice, director of Programs at the Society’s Mid South Chapter. Brice noticed Tucker’s “strong voice and winning personality” and put her in touch with Gail Lesby, a local insurance broker who was looking for a friendly, outgoing person to help her.

Now, Tucker helps keep Lesby busy by setting appointments for Lesby’s sales calls. Tucker makes 20 to 30 calls a day, depending on her energy level. At her desk is a holder that puts a mouth stick and a cell phone within her reach. She uses the stick to dial, then speaks the results to her computer: voice-recognition software enables her to update the database. Tucker’s personal aide, Princess Rhae, types any extra notes, and faxes the resulting call lists to Lesby. “A fair percentage of the people I talk to become clients,” Tucker said.

**Equipping the home office**

Linda Tucker adapted her home to make telework possible. It’s often costly: A home office probably needs an extra phone line or broadband Internet service, as well as office chairs that will sustain a workday, a hands-free telephone, and other aids. Steve Nissen often negotiates with employers to provide the right environment. State vocational rehab agencies can often provide funds and assistance. The U.S. Office of Personnel Management’s Web site, [www.telework.gov](http://www.telework.gov), houses a wealth of information, including telework resources and laws pertaining to working from home.

**Cutting out the commute**

In late 2003 Karen Jackson was going through some major transitions. Coaching had become too fatiguing and Jackson realized that she had to make a change. A surgeon she knew from her athletic work needed some help. Today, Karen takes dictation, schedules surgeries, and makes sure each procedure is “pre-authorized” by the patient’s insurance. Her experience negotiating with insurance companies on her own behalf, she said, “certainly didn’t hurt.”

On Thursdays and Fridays, when Jackson works from home, she doesn’t have the fatiguing effect of a commute in the nation’s capital. “I leave my office at 5:00 PM and sit in traffic. At home, I’m
often still at the computer at 7:30 PM and I get a lot more done.”

“This increased productivity is quite common among teleworkers with MS,” said Kim Cordingly, of the national Job Accommodation Network (JAN). Cordingly is currently studying women with MS in “alternative employment” for her doctoral dissertation. “These women can be so much more productive if they eliminate that commute,” she said.

Start slowly and carefully
Is telework right for you? Cordingly and Nissen both emphasize a careful start. You can go directly to agencies like JAN (800-526-7234, www.jan.wvu.edu), or your local and state employment and vocational rehabilitation agencies. “But you can’t make an immediate switch,” Nissen said. “You need to look at yourself and see what you have to offer, not just what you need.”

What not to do, both agree, is to jump on any random offer that promises riches for at-home work. Many are scams. They exploit workers, often using them and their computers to send borderline-illegal bulk e-mail (also known as “spam”).
How will you know?

“Just. Be. Informed,” Nissen emphasized. “If an employer wants any money up front, say no. Make sure you’re on the payroll of an actual company.” Check with the national Better Business Bureau, www.bbb.org, to make sure. And remember, if an offer sounds too good to be true, it probably is.

**Telework and benefits**

Denise Veazey, the Mary Kay associate, is acutely aware of the need for benefits planning. Veazey was once a specialist in private disability insurance before she started having paresthesia in her arms, and was diagnosed with progressive MS. Veazey moved back to her hometown in Tennessee, where she knew people and where her benefits, from SSDI and from the private disability insurance she’d purchased, would stretch further. When she wanted to return to work, she knew she would still need Medicare and other support. Mary Kay Cosmetics, with its flexible schedules, allows her to work “about three hours a day” and earn a significant income, without exceeding the maximum allowed under Social Security’s “work incentives”—currently $829 a month.

Karen Jackson is also careful to do the same: “I’m actually part time. I don’t put in more than 64 hours in a pay period,” she said.

Nissen, Anderson, and Cordingly all emphasize the crucial nature of benefits planning. Understanding the eligibility rules is important, even if you’re not receiving SSDI or Medicare and are relying on your job’s disability insurance or are hoping to start a business. Most private insurance companies take their guidance on eligibility from the Social Security Administration’s rules.

Chris Lombardi is a regular contributor to InsideMS.

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**The loneliness of the long-distance teleworker**

Working at home gives you the flexibility to work when you can, and at your own pace. But it can also be lonely, especially when the only voices you hear come through the telephone. Keeping face-to-face connections with the outside world is important.

Linda Tucker never misses a University of Texas football game and looks forward to her grandchildren’s visits, as well as the gatherings where she meets the clients she’s found for her friend and employer. Still, she allowed that “it’s hard some days.”

Karen Jackson, who said she sometimes feels she is “too attached to being home,” thinks her on-off commute schedule gives her just enough of other people to keep her sane, especially since her husband travels a lot for work.

Denise Veazey keeps herself busy in addition to her job: She participates in Women Against MS events; volunteers at a local hospital and the Boys & Girls Clubs; and meets regularly with a writers’ group.
Plan B is something everyone needs—not just people with MS. This isn’t pessimism. It’s just being realistic about life. An employment crisis could be a major MS exacerbation or a recurring symptom that shoots a hole in a former ability. It could also be industry slowdown, company downsizing, a family emergency. You need to ask yourself tough “what if” questions and answer them with concrete plans.

How do you get started?

Assess your current situation. How is your job performance? Don’t wait for a review from your supervisor. Review yourself as if you were your employer. You may conclude you’re doing fine. The next step still needs to be taken.

Assess future possibilities. What if you have a change that affects your stamina or your abilities? What kinds of adjustments could you make? Would you need training? New skills?

What resources do you have for these changes? Do you understand your employment benefits, including any training or tuition programs and when or how they can be used? Do you know what benefits your spouse has? What kind of tax hit would you take if you had to access your retirement money? What would happen to your disability or health-care benefits if you cut back to part-time employment?

What legal protections can you claim?

The National MS Society can help you find your answers. Today, every chapter has a trained employment advisor or an expert volunteer. If you have financial questions, the chapter can connect you to an advisor from the Society of Financial Service Professionals. They have agreed to provide free consultation to people with MS. Your chapter has booklets and fact sheets on the Americans with Disabilities Act, negotiation techniques, disclosure, and insurance issues. Staff members can refer you to the vocational rehabilitation programs in your state and to occupational therapists, neuropsychologists, or speech/language pathologists should you need their services.

The Society’s Career Crossroads education program is designed to help you work through issues involved in keeping your job or getting a new one.

How do you get started? Call your chapter at 1-800-344-4867.
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.

The Society publishes many other pamphlets and articles about various aspects of MS. To ask for these, or for other information, call the National MS Society at 1-800-344-4867.

All our publications are on our Web site, along with handouts called "Basic Facts" on various topics. For a list, click the bar on our home page called “Library”. If you have no access to the Internet, just call your chapter and ask for a copy of the latest Publications List.

Some of our popular pamphlets include:

- A Place in the Workforce
- ADA and People with MS
- Should I Work? Information for Employees
- The Win-Win Approach to Reasonable Accommodations
The National Multiple Sclerosis Society is dedicated to ending the devastating effects of multiple sclerosis.

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