

Career decisions



How do you know when it's time to stop working?

by Judi Hasson

Maybe you've been working full time for years while managing multiple sclerosis symptoms, even occasional flare-ups. But now, you're getting tired earlier in the day, having difficulty concentrating, facing bladder-control issues or experiencing other problems that are making it harder to do your job day in and day out. Is it time to call it quits?

It depends. Some people living with MS may be able to remain in the workforce with adaptations to their schedule, environment or duties. For others, rehabilitation or medication changes may help ease symptoms enough to keep working. But many people also decide to retire or go on disability.

The decision to stop working is never easy, and there are numerous occupational, financial, emotional and physical issues for each individual and family to consider. Here's what you need to know.

Making it work

Even if you have increasingly severe MS symptoms, you may be able to keep working if you can incorporate flexible work arrangements or accommodations that make your job less of a physical or cognitive challenge.

The Americans with Disabilities Act requires most employers with 15 or more workers to provide reasonable accommodations for qualified employees with disabilities. This can include telecommuting, changing work hours or schedules, moving a work station closer to a bathroom, providing closer parking, or shifting to a job that may be less demanding.



Kurt Johnson, PhD, says people may be able to work with their employers or healthcare providers to develop strategies to stay on the job. Photo

courtesy of Kurt Johnson

But, according to the law, you still must be able to perform essential work functions. “Work with your employer to see if there are ways to stay on the job,” advises Kurt Johnson, PhD, professor of rehabilitation medicine at the University of Washington’s School of Medicine. An employer may not generally offer such accommodations, so individuals need to be proactive in requesting them.

Seeking support

Sometimes, MS symptoms become more intense so that modifications to the work environment aren’t sufficient. Dr. Johnson says the symptoms that most commonly affect job performance are:

- Cognitive changes, such as problems with information processing, short-term memory, attention and concentration, and prioritizing, organization and decision-making
- Fatigue, which can make it difficult to complete a full workday
- Vision changes
- Depression and anxiety
- Reduced mobility
- Bowel and bladder dysfunction
- Pain

If any of these are issues for you, Dr. Johnson recommends asking your doctor about possible changes in your disease- and symptom-management plan. This may include medication adjustments, or working with a physical, occupational or speech-language therapist to further develop strategies for handling MS symptoms.



Joe Stuckey recommends turning to a vocational rehabilitation counselor to discuss career options.

Photo courtesy of Joe Stuckey

In addition, a vocational rehabilitation counselor can help evaluate how your symptoms are affecting your work, and can suggest options, individualized to your circumstances, that will maximize your chances of staying in your current job. For example, if you have challenges with afternoon fatigue, you might be able to modify your schedule to start work earlier and complete your work day before fatigue sets in, says Joe Stuckey, a certified rehabilitation counselor at the University of Washington Medical Center’s Multiple Sclerosis Center.

Stuckey says a vocational rehabilitation counselor also may be able to help you identify a job that is better aligned with your goals, strengths and health-related limitations, such as a job with a slower pace or with fewer physical or cognitive demands. If you are considering returning to work, you may even want to begin with a volunteer position.

“Volunteer jobs are excellent opportunities to increase social contact, explore occupational interests and give work a trial run before seeking a paid employment position,” he says.

The tipping point

For many people with MS, however, there comes a point when continuing to work becomes too difficult because of the disease’s progression. “We often see gradual changes over time—an accumulation of challenges that raise the question of when to stop working,”

Stuckey says. While the contributing factors vary for each person, the following are some of the most common indicators that it may be time to consider leaving work altogether.

- **Absenteeism.** You're missing work more often due to your MS symptoms, which creates stressful challenges for you and your colleagues. Also, if you're eligible for the Family & Medical Leave Act, you could be legally terminated for absences after your 12 weeks of annual medical leave are exhausted.
- **Lack of effective employment modifications.** The coping strategies and tools you've implemented are no longer effective. Maybe you're even working longer hours to try to meet the job's demands.
- **Job performance challenges.** You're making more errors in your work, have received poor performance reviews or other negative feedback, or simply are unable to meet the physical or cognitive job demands. In such instances, you may prefer to leave on your own terms before your employer makes the decision for you.
- **Work-life imbalance.** You're spending most of your energy at work, leaving other life needs unmet.
- **Decreasing quality of life.** You're feeling overwhelmed by the impact of your MS symptoms on both your professional and private life, and it's a struggle to keep working.



Thinking about leaving a job can give rise to a range of emotions, so it can be helpful to consult a mental health professional, says clinical psychologist Peggy Crawford, PhD. Photo

courtesy of
Peggy Crawford

Family business

Several other factors are important to consider when deciding whether to leave your job, including the effect this major life change will have on your family, finances and mental health.

“Sometimes people with MS find they are able to make a greater contribution at home once they are no longer exhausted from work,” says Peggy Crawford, PhD, a Boston and Maine-based clinical psychologist with 25 years of experience working with people with MS.

The expectations around—and time available for—social and family activities may also shift.

That’s why Dr. Johnson encourages people who are considering leaving their jobs to talk with a rehabilitation counselor or psychologist first.

“We ask people to bring spouses, partners and adult children along to meetings with us, because this is usually a family decision and has significant implications for everyone,” he says.

Crunching the numbers

It’s also essential to understand how your finances will be affected if you stop working. Surprisingly, that piece of the picture is often overlooked, says Martin Shenkman, a New Jersey lawyer and author of **Estate Planning for People with a Chronic Condition or Disability** (Demos Health, 2009). He says many people with MS are focused on their deteriorating health and daily living, so financial planning takes a back seat.



**Before
deciding to
stop working,
do some
financial
planning,
says
Martin**

Shenkman.

Photo courtesy
of Martin
Shenkman

“Do not stop working if you absolutely don’t have to, unless you first complete a budget and financial projection. Sometimes, holding on for as little as six to 12 more months can create a significant difference in your financial security over the next two decades,” Shenkman says.

He recommends that people with MS take several important steps before deciding to exit the workforce:

- **Calculate** your projected monthly expenses and the income you will have from all sources, including savings, pension or 401(k) assets, a disability income replacement policy, or a spouse’s income. Create a budget to see if the numbers work. If they don’t, find ways to cut expenses.
- **Determine** the long-term costs of staying in your present home—and making it fully accessible now or in the future. Consider whether you could cut expenses, perhaps by refinancing your mortgage or moving to a more affordable (and possibly more accessible) residence.
- **Evaluate** your health insurance options and consider whether you can work enough hours, perhaps in a different job with a more flexible schedule or accommodations, to generate some income and maintain health coverage through your employer. If not, look into options such as obtaining health insurance through the Affordable Care Act, Medicare or Medicaid. It’s also a good idea to evaluate disability insurance policies.
- **Review** benefits you currently have through your employer, such as a term life insurance policy, and determine whether they will carry over after you leave.
- **Consider** applying for Social Security Disability Insurance (SSDI). But be aware that it can take quite a while to begin receiving benefits. Call an MS Navigator at 1-800-344-4867 to discuss when you should apply for SSDI —and for help understanding the application process. Navigators can also refer you to the no-cost Financial Education Partners program for help with other financial considerations.
- **Consult** with a financial adviser if you have investments to determine whether your current portfolio will meet your short- and long-term needs.

Social and emotional health

Another important factor to consider before leaving your job is how this transition will affect you emotionally and socially. “Since many people contemplating this decision are already experiencing depression and anxiety, it can be very helpful to engage in even brief counseling with a mental health professional,” Dr. Crawford suggests.

Stuckey adds: “Stepping out of the world of work can feel like the loss of part of our identity. The question, ‘Who am I now that I am no longer working?’ is very common. For many, there

is a sense of grief over the loss of the ability to work. Concerns about the impact of the loss of income on the family or how one contributes to society can lead to feelings of a loss of self-worth. Some may feel a lack of purpose, or struggle to establish new daily routines. For some, a sense of isolation and low mood may occur,” particularly as work-based friendships take less of a central role. For all of these changes, there’s a process of acceptance and adjustment, he says.

Talking to a psychologist or your rehabilitation counselor can help. “Together, you can develop an individualized plan—including counseling support, volunteer opportunities and a wide range of social activities geared toward these life changes—to help improve your quality of life,” Stuckey says.

The emotional reaction to leaving a job is not always negative, however. “For many people, leaving a job where they are struggling to keep up and get through the day reduces their stress,” says Dr. Crawford. “People often find that they feel better physically and emotionally. Many also find new purpose through volunteering and spending more time with family and friends.”

That was the case for Janice Yohai, 57, of Annandale, Virginia, who stopped working as a direct marketing consultant in 1997, six years after her diagnosis. “I no longer trusted myself when advising my clients. I could no longer forecast, manage details or meet tight production schedules,” Yohai says. “There were no tears; there was no regret or loss. I welcomed it because I couldn’t do [my job] anymore.”

A graceful exit

But Yohai also took steps to ensure she still felt useful. She now writes a blog about MS and volunteers for voter registration work. It was part of her “exit strategy”—something that Drs. Johnson and Crawford say is critical to develop before you quit your job. They say a good exit strategy should include:

- Involving family members as full participants in the decision. They’ll need to understand the consequences and provide support.
- Figuring out possible changes in roles and responsibilities at home.
- Ensuring you have some structure in your day. While one of the perks of leaving work is the ability to sleep in, it’s helpful for people to find a way to engage in activities that are meaningful to them.
- Reaching out to friends to strengthen support and social opportunities.
- Exploring new opportunities for creative endeavors, volunteer work and developing new friendships.

While there are many issues to consider, the bottom line is that when work is no longer sustainable due to the impact of MS, life is out of balance. And, as Stuckey notes, “the decision to leave work is truly about rebalancing one’s life.”

Judi Hasson is a Washington, D.C.-based freelance writer who was diagnosed with MS in 2007. Additional reporting by Laurie Budgar, editor of Momentum.

For referrals or assistance with vocational or financial concerns, call an MS Navigator at 1-800-344-4867. You can also visit the [Job Accommodation Network](#) website for tips on managing symptoms on the job and to identify your state's vocational rehabilitation agency. To learn more, register for the Feb. 9 web & telelearning seminar, "Navigating Career Change," presented by the Society and Can Do MS. Visit nationalMSsociety.org/telelearning to sign up.

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