

Work it



**You might not have to quit your job after all.
Vocational rehabilitation helps people with MS explore
their employment options.**

by Vicky Umland

Debi Capwell thinks she began having multiple sclerosis symptoms as a teenager. But she wasn't diagnosed until she was in her early 40s, after her foot drop became so severe that she was afraid she wouldn't be able to walk well enough to continue her career as a home-health nurse.



Debi Capwell applied to her state's office of vocational rehabilitation to acquire an FES device free of charge. Photo by Dave Moser

"I wanted to find ways to improve my foot drop and keep my job," she says. "After 27 years as a nurse, I felt like without a job, I would feel useless. And I feel better if I go into work because I know I'll have things to do, and I'll be up on my feet and walking. When I'm at home, I'm tired, and I just want to sit on the couch."

Capwell tried physical therapy, but it had little effect on her foot drop. She researched and decided that a functional electrical stimulator (FES) device was her best option. But with a \$7,500 price tag, the device was out of reach for her budget.

Then, one of Capwell's patients suggested she look into vocational rehabilitation services. Capwell, who lives near Scranton, Pennsylvania, applied to the state's office of vocational rehabilitation. After meeting with a counselor and providing some basic information about her disability, living situation, income and career interests, Capwell acquired an FES device free of charge.

"It was a pretty smooth process and only took about a month," she says. "Now, my foot drop is much better, and I get to keep my job."

Help explore your options

People living with MS might give up their jobs without fully exploring how they could continue working. Vocational rehabilitation services can help you explore your options — and maybe stay employed.

A few years ago, a pair of university professors set out to produce a thorough employment and MS assessment. They surveyed nearly 2,000 American adults living with MS and discovered some alarming statistics.

At the time of their diagnosis, 82% of people with MS had a paying job. Five years after their diagnosis, only about 40% were employed.

Many of these people — 75% — left their jobs voluntarily, but 80% felt they still could work.

About 75% of the study participants wanted to go back to work.



Phillip Rumrill, PhD, notes that people with MS are juggling a lot when first diagnosed.

“They quit while they could still work and ended up regretting that decision,” says Phillip Rumrill, PhD, professor of counselor education and director of research and training in the Human Development Institute at the University of Kentucky. Rumrill and Malachy Bishop, PhD, a professor in the Rehabilitation Psychology and Special Education Department at the University of Wisconsin-Madison, conducted the study published in 2015 in the journal *Work*.

The number of people with MS who wish they were still in the workforce is so high that Rumrill and Bishop believe it’s a public health issue.

“Employment is an important part of life for most people,” Bishop says. “It contributes to our identity and income, and it provides benefits like health insurance, the opportunity to interact with others socially and a way to be productive and contribute to our community.”

Rumrill says research shows that many people with MS are well-educated and highly trained in their jobs. “Society is losing out on the really valuable resource of workers with MS,” he says. “We all benefit when people with MS work as long as they want to.”

Bishop cites a study he, Rumrill and others conducted that was published in 2019 in the *Journal of Vocational Rehabilitation*.

“We found that employment was one of the top contributors to quality of life for people with MS,” Bishop says. “Researchers are increasingly looking at the relationship between work and health and finding that work is an important contributor to health as well.

“But for too many people living with MS, the loss of employment is an unnecessary result of the diagnosis.”

Rumrill points out that when people are newly diagnosed, they might juggle a lot of emotion,

information and advice from friends and family. “Sometimes people think quitting work is the easiest choice,” he says.

But hasty decisions are a big reason why so many people with MS who leave their jobs later have regrets. It’s why Bishop and Rumrill are evangelists about ensuring that people with MS know all of their options before making employment choices.

“If you choose to stay working, we want to help you. If you choose to stop working, we want to help you,” Rumrill says. “And we believe the best way to do all of that is through vocational rehabilitation services.”

Lack of an exit strategy

Many people with MS leave their jobs because of physical, mental or emotional symptoms. In their 2015 study, Bishop and Rumrill cited data showing that almost 50% of people with MS who quit their jobs did so because of ambulatory issues. Between 30% and 39% said fatigue was the most critical factor. People with cognitive impairments were four times more likely to be unemployed. Depression and anxiety were also factors.



Malachy Bishop, PhD, says work is a top contributor to quality of life.

Rumrill and Bishop’s research shows that people with lower incomes and levels of education may have jobs that require more physical exertion and thus feel more pressure to quit before their physiological symptoms worsen. People who have a spouse who’s working tend to leave their jobs more often than those who don’t.

Meanwhile, people higher up on the job scale may have the flexibility and authority to adjust their schedules to accommodate their symptoms — and keep their jobs.

“The reasons people with MS stop working vary widely and are personal and individual, but the barriers they face to continue employment can often be addressed,” Bishop says. “I have

spoken with many people with MS over the years who found that stopping working was the right choice for them. But unfortunately, many people with MS decide to stop working without access to the information they need to plan for their futures.”

That’s where vocational rehabilitation comes in.

Services that help

The U.S. Vocational Rehabilitation (VR) Program dates back to 1920 and is funded through a partnership between federal and state governments. Today, every state has a vocational rehab agency, often with multiple offices. The agencies may have different names in different states, like the Office of Vocational Rehabilitation or the Department of Vocational Rehabilitation, but they all fall under the same umbrella.

The VR Program is designed to help people with disabilities or chronic illnesses keep their jobs or find new jobs. Its services are extensive, and many are free.

If you’re debating whether to continue working, your local VR office can help you with long-term planning. It can provide financial and benefits counseling and help you evaluate the psychological and social aspects of keeping or quitting your job.

VR can offer specialized tests and assessments that identify workplace accommodations you may need for your specific MS symptoms now or later if you want to continue working. A counselor can work with your employer to implement those accommodations. If you haven’t revealed your diagnosis to your employer, VR programs can supply you with assistive technology, devices, tutors or other aids to reduce work barriers on your own. VR also can provide services like work transportation or housing modifications that allow you to work at home.

If you’re thinking about changing careers to a less-demanding job, VR can help you identify transferrable skills. It offers job counseling, tests and guidance. It can hook you up with vocational training and education and help you identify and apply for a new job.

And if you choose to stop working, VR can help with volunteer opportunities or finding new activities and hobbies.

“There are a lot of potential benefits to reaching out to VR, but I think the biggest benefit people with MS can get is the ability to make the most informed decision possible about their future and their careers,” Bishop says.

How to get in the door

Essentially, anyone who has a physical or mental impairment that causes problems with working may be eligible for VR services. Requirements vary by state, but all you may need is a doctor’s letter stating your impairment. People receiving Social Security income or disability insurance qualify automatically. Still, they need to show documentation of three limitations to be eligible for this category of disability.

Sharon Silverman, vocational rehabilitation supervisor for Pennsylvania's Office of Vocational Rehabilitation, says MS symptoms can be very specific to the individual and lead to different limitations for different people. VR offers forms that health providers can complete.

Along with stating the diagnosis and the prognosis, the provider is asked questions like how long their patient can sit, stand or walk; what type of work tasks the patient can or can't do; and whether the patient may have difficulty working more than 20 hours a week.

Once the Pennsylvania office of VR has that documentation and determines eligibility and where the individual falls in their order of selection, a counselor meets with the new client and maps out a vocational rehabilitation plan. Bishop says the vast majority of VR counselors have master's degrees and all are trained in vocational and career planning and medical and psychosocial aspects of disability and chronic illness.

Despite the relative ease of applying for VR programs, Rumrill says people with MS tend not to use VR services — or even know they can.

The hidden resource

One of the biggest reasons why people with MS aren't VR customers is because they don't view themselves as disabled — especially in the early stages of their disease. "You may need a little healthy denial to get through this illness," Rumrill says.



Joe Stuckey, a rehabilitation counselor, says it's natural for people with MS to deny work challenges.

Another issue is that doctors who work with people with MS may not know about VR services or recommend them. According to Rumrill, the No. 1 answer given when people with MS are asked why they quit their jobs is their doctor recommended it. "Your neurologist may say you need to quit working because of the stress," he says. "But most neurologists are

unacquainted with the stress of being unemployed.”

Joe Stuckey, a rehabilitation counselor at the University of Washington Medical Center in Seattle, says it’s a natural coping strategy for people with MS to deny or minimize their work challenges.

“Folks have a lot of fear and uncertainty about the impact of MS on their work, but many times they may not even report work issues to their healthcare provider. They may assume their work difficulties are due to something else, like aging,” he says. “So, they wait until a crisis, like a negative performance review or negative feedback from a manager or colleagues. And then there’s the risk that their perceived value to their employer has diminished.”

Bishop says another issue is that because funding is limited, VR programs prioritize services for those who have the most significant work barriers. Someone with mild MS symptoms may be pushed further down the line. While it’s a good idea to access VR services while you’re still working, VR also can help people who want to rejoin the workforce.

The benefits of early admission

A study published in 2015 in *Rehabilitation Research, Policy, and Education* reported that about 70% of people with MS weren’t working when they applied to a VR program. But those who utilized VR while they still had a job saw increases in their average weekly earnings and average number of hours worked.

“About 70% of clients in this group were able to retain their jobs or find new jobs after receiving VR services,” Bishop says. “Unfortunately, for several reasons, the numbers are somewhat lower for people who have stopped working.”

Rumrill says one of those reasons is that “every day someone’s disengaged from the workforce, they feel more disconnected, both mentally and physically. Job retention works best sooner in the disease process, when people still are relatively healthy and still think of themselves as workers. Once you get on disability or Social Security income, you don’t tend to go back.”

Another reason is universal and doesn’t apply only to people with MS. It’s easier to help someone keep their job than to help them restart their career. But as any mother who re-enters the workforce after taking time off to raise a child knows, it’s not impossible.

Still, there can be red tape and delays with government-run VR services. Rumrill says it can take as long as six to eight weeks for a VR office to determine whether an applicant is eligible for services. That’s why some people opt for VR programs at universities and clinics financed by health insurance.

Some large healthcare facilities with MS programs provide VR services as part of their overall rehabilitation services.

NYU Langone Health is a major academic medical center that offers VR services through its Rusk Rehabilitation Program. Vocational Rehabilitation Director Robert Lindsey says the department is a private nonprofit partially funded by the state VR agency.

People who want to use NYU VR services need a referral from their doctor, the state VR agency and the Department of Veterans Affairs. Individuals are accepted on a case-by-case basis. “But I’ve never seen anyone with an MS diagnosis turned down for an initial assessment,” Lindsey says.

The NYU VR program offers services similar to state programs, including vocational evaluation, work readiness training and job placement, and people with MS may work with counselors for years if necessary, Lindsey says. “Vocational rehabilitation is particularly suited to people with MS because it can address symptoms at different stages of the disease.”

The University of Washington Medical Center’s Rehabilitation Counseling VR program is part of a multidisciplinary medical approach for MS that includes physical therapy, speech therapy, occupational therapy and psychological counseling. Services are hospital clinic-based and billed to health insurance. Like the NYU program, the UW program partners with the state VR office.

During the initial visit with a new patient, Stuckey conducts a thorough review of symptoms and disease progression. Other discussion points include employment, education and life activities with both the patient and their family.

“Because most people are diagnosed with MS during their key working years, I get a good bit of job questions,” he says. “I’ve found that if I can meet with folks early on in their disease and do early intervention work, it’s a big factor in sustaining employment and increasing confidence and acceptance of the disease.”

Stuckey believes people with MS can benefit significantly from VR services. “Health status can change very quickly when you have MS, which can lead to employment emergencies that vocational rehabilitation can address.”

Online options

The National Multiple Sclerosis Society has [MS Navigators](#) who can also help find programs near you. You can reach them by calling 1-800-344-4867.

There are MS Navigators who specialize in benefits, employment and health insurance-related needs. The Society has information related to [employment needs on its website](#), including a brochure “The Win-Win Approach to Reasonable Accommodations.”

VR counselors are also big fans of the [Job Accommodation Network \(JAN\)](#), a free online

service for anyone with a disability. You can find a VR program in your state by searching [“state vocational rehabilitation agencies.”](#)

“JAN is our federal government’s most successful vocational rehabilitation network,” says Phillip Rumrill, PhD, a professor of counselor education at the University of Kentucky. “You can talk to vocational rehab counselors by online chat, email or phone. You can search for general MS topics or by specific symptoms.”

A search for “multiple sclerosis” gives information on how the Americans With Disabilities Act applies to MS, along with lists of specific job accommodations for common symptoms. For instance, “decreased stamina and fatigue” turns up 26 solutions ranging from anti-fatigue matting to low-task chairs to work site redesign.

There are resources for job seekers and people who want to start their own businesses. You can search by disability, limitation, work-related function or accommodation needed. You can also create your own portal to keep all of your JAN information in one place.

Whether you opt for an in-person or virtual VR counselor or a public or private VR program, employment experts say you can gain valuable tools to help make the best choices about your work life now and in the future.

“MS changes the level of control you have over your health, so why not take steps to control your career?” says Phillip Rumrill, PhD.

Vicky Uhland is a writer and editor in Lafayette, Colorado.