

Employment and Multiple Sclerosis

People with MS are a qualified and experienced group of workers. Experts estimate the current rate of labor force participation among Americans with MS to be between 30% and 45%. More than 90% of Americans with MS have employment histories with two thirds working at the time of diagnosis. Half of all people with MS stop working within the first five years of diagnosis. However, some 75% of unemployed people with MS feel that they would like to return to work, and more than 80% believe that they are able to work. Some studies report that the majority of unemployed people with MS voluntarily leave the workforce, as high as 80% in some studies. In other words, these experienced and productive workers tend to voluntarily leave the labor force, often prematurely, and then regret the decision. This question and answer fact sheet will answer some of the frequently asked questions related to individuals with MS and employment.

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QUESTION: What is multiple sclerosis?

ANSWER: MS is one of the most common neurological diseases in the world. MS is a degenerative disease of the central nervous system, primarily affecting the brain and spinal cord. A fatty tissue called myelin surrounds the white matter tracts (i.e., axons) in multiple locations in the brain and along the spinal cord. The purpose of the myelin is to facilitate conduction of electrical impulses back and forth from the brain to the rest of the body via the spinal cord. If a person has MS, the myelin can be destroyed or compromised resulting in electrical impulses not being conveyed effectively. This slowed or blocked conduction of information can influence a person's physical, sensory, mental, and emotional activity. Common symptoms of MS include fatigue, hypersensitivity to heat, spasticity, mobility impairments, visual impairments, sexual dysfunction, bowel and bladder dysfunction, chronic pain, numbness and tingling in the extremities, diminished physical strength, cognitive impairments, depression, anxiety, and bipolar disorder. Typically, MS symptoms come and go in an unpredictable pattern of relapses and remissions. In many cases, the effects of MS are progressive, resulting in a decline in the person's overall health status over time.

QUESTION: How many people in the United States are impacted with MS?

ANSWER: The National Multiple Sclerosis (MS) Society estimates that there are approximately 400,000 people with MS in the United States. This means that approximately 1 in 750 Americans are living with MS at any given time. It has been estimated that 10,000 individuals are diagnosed each year in the United States, and this rate of incidence has steadily increased since the 1950s. This increased rate of detection has been attributed to the development and refinement of diagnostic tools such as magnetic resonance imaging (MRI).

Although MS can occur at any age, initial symptoms are evident most often during early adulthood, between the ages of 20 and 40. This is the time when many individuals are beginning or building their careers. Women are more than twice as likely as men to acquire MS. People of European descent are more likely to have MS than individuals from other racial and ethnic groups.



QUESTION: Should a person stop working when diagnosed with MS?

ANSWER: There is no reason for a person to stop working after being diagnosed with MS. No evidence suggests that employment has a negative effect on a person's health status. In fact, many experts believe that people who work are psychologically and physically healthier than those who do not. With advancements in assistive technology, medical treatment, and societal attitudes toward people with disabilities, people with MS and other disabilities are able to maintain their jobs longer than ever before.

There are also laws in place, including the Americans with Disabilities Act (ADA) and the Family and Medical Leave Act, to help a person keep working. If and when someone decides to stop working, it is important that all relevant factors are considered (e.g., family circumstances, financial needs, health status) with input from significant others, health care professionals, and the employer. The individual will know better than anyone else when and if it is time to stop working.

QUESTION: How can the ADA help a person with MS continue working?

ANSWER: The ADA of 1990 was the first comprehensive legislation passed by any country in the world to prohibit discrimination on the basis of disability. As it pertains to employment, the ADA requires employers with 15 or more employees to provide reasonable accommodations for qualified employees with disabilities. Although reasonable accommodations are an important part of the ADA, the employment protections available to people with disabilities go far beyond on-the-job accommodations. Under Title I of the ADA (the employment section), people with disabilities have the civil right to enjoy the same benefits and privileges of employment as their nondisabled coworkers. This means that personnel decisions (e.g., hiring, promotion, layoff, termination) must be made without regard to the person's disability status. Workers may not be harassed on the basis of their disabilities, and the compensation received must be commensurate with their qualifications and productivity irrespective of disability.

QUESTION: How are reasonable accommodations determined for someone with MS?

ANSWER: Reasonable accommodations are determined on a case-by-case basis. Before becoming eligible for a reasonable accommodation, the worker or applicant with MS must disclose his or her disability status to the employer and make a request for the accommodation. This does not mean, however, that the person must initially disclose his or her underlying diagnosis or disabling condition. If an employer requires additional information, including diagnosis, to document a person's disability status, he or she may need to provide medical verification of accommodation needs. Employees or job applicants with MS are encouraged to accompany disclosure of their disability status with a specific plan for accommodations. The plan should include details or description of the type of accommodations that would be most beneficial. This eliminates the employer's uncertainty of what needs to be done and may allow him or her to better understand how the accommodation will assist the employee in completing the essential functions of the job. Employers may be more likely to approve an identified strategy than they are to determine what the person's needs are.

QUESTION: Does an employer have to make all accommodations that a person requests?

ANSWER: An employer may not be required to make all accommodations that are requested. For example, employers are not required to eliminate an essential job function from a person's job description. Essential functions are the fundamental, crucial job duties performed in a position. Production standards do not have to be lowered for an employee with MS if these standards exist for all employees. An employer does not have to provide personal items (e.g., a cane, wheelchair, eyeglasses) unless those items are required only for work purposes. An employer does not have to excuse a violation of conduct rules because the person has a disability.

Finally, the employer does not have to provide accommodations that constitute an undue hardship (i.e., changes or modifications that would prove too costly or disruptive to the operation of the business). Undue hardship refers to accommodations that would be too expensive or disruptive for a particular business to handle. In most cases, the employer is required to pay the costs of the accommodation. Keep in mind that research indicates that the majority of on-the-job accommodations used by people with MS cost nothing or very little to implement.

As previously mentioned, accommodations are determined on a case by case basis. An employer may not be required to make an accommodation under the ADA, but voluntarily does so based on the benefits of hiring or retaining the worker with MS. For instance, an employer may eliminate an essential job function from a person's job description and add another one because it benefits the business.

QUESTION: Does a person with MS have to disclose during a job interview?

ANSWER: The issue of disclosure is one of the most important, and potentially complicated, employment concerns for people with MS. As a matter of law, a person has no obligation to disclose anything about disability status or underlying diagnosis during a job interview unless the person requires an accommodation for the interview itself. A prospective employer does not have the right to know your diagnosis, and people with MS and other disabilities are generally encouraged to leave medical information out of any discussion with a prospective employer.

If a person's disability is not obvious to the employer, and the person does not foresee any need for reasonable accommodations, there is generally no reason to mention disability at all. If symptoms do not affect the person's job performance, is it any of the employer's business? This is no different than a person's religious beliefs or credit history as examples. These issues have no bearing on a person's ability to do the job, and they would not be mentioned during an interview. In other words, each person should maintain his or her right to privacy. A person can always add more information about disability status if the situation calls for it. But, it is impossible to recapture privacy if a person makes a full disclosure during a job interview.

The only time a person with MS needs to disclose is when he or she needs a reasonable accommodation to perform one or more of the job's essential functions. If the disability is obvious, and if the person is certain that on-the-job accommodations will be needed, the person may wish to mention the accommodation needs during an interview. If the individual decides to disclose during the interview because an accommodation is needed, it is important to focus on the skills and techniques that person uses that will allow him or her to perform the job.

QUESTION: What is the procedure for requesting reasonable accommodations?

ANSWER: When a qualified individual with a disability requests an accommodation, the employer must make a reasonable effort to provide an accommodation that is effective for that individual.

Ideally, the person with MS and the employer make a joint and mutually acceptable decision regarding which accommodations to implement. Title I of the ADA requires that employee and employer engage in a cooperative dialog to assess the worker's needs, identify accommodation options, and implement a reasonable accommodation that is agreeable to both parties. During this process, input can be sought from medical professionals, unions, and if the collaborative process has broken down, attorneys. In general, the accommodation process works best when most of the decision-making is done by the employee and employer, with a minimum of assistance from partisan advocates. Other resources that might be enlisted in identifying cost-effective accommodations include rehabilitation counselors, assistive technology specialists, rehabilitation engineers, ergonomists (specialists in the study of workplace design and safety), the Job Accommodation Network, and physical therapists or occupational therapists.

QUESTION: What are common issues that people with MS may have in doing their jobs?

ANSWER: Two of the most common problems related to job performance among people with MS have to do with fatigue and cognitive impairments. These are two of the most frequently reported MS symptoms. The most frequently used workplace accommodation among people with MS has to do with schedule modifications. This may include 1) reducing hours at work, 2) working from home when their MS makes it difficult for them to come into work, 3) taking an extended lunch break to rest and regain energy, or 4) modifying the number of shifts worked in a week (e.g., same number of total hours but more, shorter shifts). They also may benefit from electronic memory aids that can be programmed into computers, iPads, and/or smart phones to help them organize their time and work tasks.

People with MS frequently report the need for physical accessibility in the workplace. Accommodation strategies in this area may include the use of a motorized scooter, a four-point walking cane, and an ergonomically designed work station. Renovations to employee washrooms, entrances, parking lots, and other common areas are also helpful for workers with MS who use scooters or wheelchairs.

Some individuals with MS have difficulty regulating their internal body temperature. These individuals may benefit from cooling vests, personal fans, or access to regulating the temperature in their work areas. Computer software such as large-print and voice-output programs may be helpful for workers with MS who have visual impairments. Regardless of the accommodation strategy, effective and open communication between the worker with MS and his or her employer is the best solution to solving accommodation needs.

QUESTION: What agencies can help a person with MS in seeking, securing, and/or maintaining employment?

ANSWER: The best place to start for employment assistance is the state-Federal Vocational Rehabilitation (VR) program. Although this is a program mandated by federal law, it is carried out by individually created state agencies. Each state agency has its own name and slightly different program.

VR services are defined as an eligibility program rather than an entitlement program. This means that a person must demonstrate eligibility by having a physical or mental impairment that results in a substantial impediment to employment. There must also be a reasonable expectation that VR services can help the individual become employed. As can be seen in the wording of these criteria, there will obviously be some variation from agency to agency in determining a person's eligibility. Many VR agencies operate under an order of selection mandate, whereby services are prioritized for applicants who have the most severe disabilities. Services that may be provided by the VR program include:

- A thorough rehabilitation evaluation to determine extent of disability and need for treatment to correct or reduce the disability,
- Vocational guidance and counseling,
- Medical appliances and prosthetic devices, if needed, to increase your ability to work,
- Vocational training to prepare you for gainful employment,
- Provision of occupational equipment and tools,
- Job placement and follow-up,
- Post-employment services.

The strength of the VR program is its flexibility and its ability to respond to the allowance for provision of "other services as needed" in formulating an Individualized Plan for Employment (IPE). The challenge faced by the VR system is the need to be responsive to large number of people with disabilities seeking employment assistance with a limited amount of authorized funding. The VR services, which are potentially available for an individual with MS, can vary substantially from person to person and is dependent on a number of individual factors that are identified in the IPE. The VR counselor can help an individual with MS explore the possibilities for employment, connect with a variety of resources within and outside of the VR agency that can be supportive, and potentially arrange for financial participation by the VR agency as a component of the employment plan. The first step is to contact the VR program in the person's state to ask for information about eligibility and application procedures.

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