



Workplace Accommodations for People Living with Multiple Sclerosis

Multiple Sclerosis (MS) is a chronic and often disabling disease of the central nervous system that affects between 250,000 and 350,000 people living in the U.S. MS is most commonly diagnosed in Caucasian women from northern European backgrounds who are between the ages of 18 and 30. People living with MS are employed at a much lower rate than others. Although 95% of people with MS have a history of employment, in surveys of people 5 to 15 years after diagnosis, fewer than 25% are working. There are a number of reasons for this high unemployment rate, but it is clear that many people with MS would prefer to be working and could work productively with fairly minor accommodations in the workplace.

What is MS?

MS is a chronic disease characterized by the progressive destruction of the “white” matter in the nervous system – the myelin sheath that protects the nerves and allows for uninterrupted transmission of nerve impulses. This progressive demyelination is initially an inflammatory process that ultimately leads to the destruction of the nerve. The initial inflammation is called an “exacerbation” and can often be treated using medications to reduce the residual damage. MS is now thought to be an autoimmune disorder that develops from a complex interaction of early exposure to multiple viruses and a genetic vulnerability. There are new medications and other treatments

that seem to be effective in altering the course of the disease for many people living with MS. Researchers believe a cure is on the not-too-distant horizon. It is critical that employers and co-workers understand that MS is not a contagious disease: it cannot be transmitted to others under any circumstances.

What are the different courses MS takes?

There are three primary courses MS can take. With the “relapsing-remitting” course, people experience “relapses” or “attacks” of symptoms, also called exacerbations. People experience partial or total recovery of function after these exacerbations. This is the most common form of MS in the

U.S. For some people, the progressive as they get older – that is, the relapses are less noticeable and the symptoms progress steadily. This is the “secondary progressive” course. A minority of people with MS have the “primary progressive” course in which symptoms progress without remission. Understanding which course MS is taking is critical to designing effective employment accommodations.

What are the symptoms or limitations associated with MS?

It is impossible to predict which symptoms an individual with MS will have, and individuals may experience symptoms or limitations during an exacerbation that either resolve or are less troubling during remission. Because MS is a disease of the central nervous system, it can cause many kinds of limitations depending on where the “flare” up occurs. The most common limitation people living with MS report is fatigue – what people with MS call *MS fatigue* because it is more profound than the fatigue with which most people are familiar. People can also experience difficulty walking, using their hands, or with vision. Some people have difficulty controlling their bladders or bowels. Balance can be affected, as can sensation (e.g., in one’s hands or fingertips). One troubling limitation experienced by some people living with MS is related to cognitive changes, which can include problems with memory, handling multiple tasks, and thinking and responding quickly.

relapsing-remitting course becomes. It is important that family members, employers, and co-workers remember that because most people living with MS have relapsing and remitting symptoms, an individual may experience significant fatigue, vision changes, problems walking, and memory problems during an exacerbation and have many of those limitations resolve a week or two following treatment with medication and rest. In many ways, the unpredictability of the disease, and the difficulty others have in “seeing” the limitations are as disabling as the limitations themselves. For many, living with MS is living with an invisible disability – a disability that is difficult for the individual to understand and even more difficult for employers, co-workers, and others to grasp. And yet, when both the individual with MS and others are fully informed, the individual may well be able to continue working properly.

Accommodations

Title I of the Americans with Disabilities Act (ADA) protects qualified individuals with disabilities against discrimination in employment on the basis of disability. While the determination of whether a person has a disability (which must take into account mitigating measures such as medication), or is qualified for the position in question must always be made on a case-by-case basis, many people with MS would be considered “qualified individuals with disabilities” under the ADA. By definition, a

qualified individual with a disability must be able to do the essential job functions of the job with or without reasonable accommodation. Successful accommodations are often minor, requiring little or no expense. Successful accommodations must always be conceived and implemented in collaboration with the employee with MS – this employee has the most expertise on his or her own disease, limitations, and potentially successful accommodations. In fact, most people with MS have developed and employed a variety of informal accommodations on their own. Employees with MS also may require accommodations for several limitations and it is important that these accommodations be coordinated.

Fatigue

During or immediately after an exacerbation, an individual may feel profoundly fatigued most of the time and may need to limit work activities for several weeks. At other times, the employee will often be able to describe times when he or she has the most energy. It is not unusual for individuals to report that their “best times” are in the morning and that they become progressively more fatigued during the day. Modifying the schedule of work activities so that the employee can engage in tasks demanding more physical and cognitive effort in the morning may be useful. Strategies to provide an “economy” of energy also may be of

benefit. For example, reducing the amount of travel necessary by combining trips to the photocopy machine, or trips out of the building, or using a powered scooter for trips more than 10 feet from the desk may conserve energy. Built in rest time can be very useful. Many people living with MS report that even brief 10-minute rests can help them make it through the day. The trick is to schedule rest frequently enough to disrupt the development of more significant fatigue. The option to work at home can be very helpful since the process of getting to and from work requires significant energy. Many people with MS report that if they can work for a portion of the workday or workweek from home, they are more productive and less fatigued. Regardless of the work setting, the ergonomic accommodations described next also limit fatigue.

Motor Weakness

An ergonomic work environment is a critical first step in the accommodation process. Ensure that the employee is properly positioned in the seat to minimize pain and fatigue, and that tasks in which the employee must engage are ergonomically positioned. When considering an office setting, this includes not only the keyboard, but also the computer mouse, alternative computer access tools, monitor height, etc. A number of reasonably priced adjustable workstations are now available that allow the

keyboard, mouse, and monitor to be positioned independently. Some employees will find that using voice recognition software such as Dragon Naturally Speaking is helpful. This software allows the employee to dictate text to the computer. With either voice recognition or keyboarding, computer use becomes more efficient when routine tasks are automated using macro language. For example, in Microsoft Word, the autotext feature may be employed so that the user can substitute a two or three letter combination for blocks of frequently used text. Using compressed keyboards may reduce fatigue and alternative mouse devices may improve access to the computer. An employee can try out a variety of off-the-shelf devices at most well-stocked computer stores. The employee may want to consider keeping some type of power mobility at work, such as a scooter or power chair, to facilitate travel within the workplace. Similar considerations should be made in other work settings as well.

Vision Changes

Vision changes are often transitory but vision may deteriorate over time. High quality computer monitors with good contrast provide a good foundation for a computer station. Screen enlargement software and contrast enhancement is built into operating systems such as Microsoft WIN98 and WIN2000. Excellent screen enlargement software, which also “reads” to the user with

synthesized speech, is available from vendors such as ZoomText. Closed Circuit TV (CCTV) can be used to enhance the contrast and size of print for employees. Various fixed and moveable lenses can allow people to magnify their work. Accommodating vision changes often requires consultation with a specialist in low vision.

Bowel and Bladder Control

These issues are usually managed by the employee and the employee’s medical team. As an accommodation, the employer may need to provide easy access to the restroom, an opportunity to carefully schedule meals, and perhaps the option to work at home during times when bowel and bladder problems could be more acute.

Changes in Sensation

The most common workplace accommodation for changes in sensation would be related to loss of sensation in the fingers and hands. This loss of sensation would often be accompanied by a loss of strength. For someone with decreased sensation, it is more difficult to type accurately and manipulate small objects. Keyboarding can be enhanced by placing Velcro or other tactile stimuli on “location” keys, or by using software which gives confirmation of keystrokes. Experimenting with different computer pointing devices such as joysticks may also be useful. Some people will find the voice recognition

systems described earlier helpful in reducing the amount of keyboarding required. For assembly work or related tasks, jigs may be designed to hold or guide objects and small parts.

Cognitive Changes

The idea of requiring accommodation for cognitive changes may be frightening for an employee, but many of these accommodations are quite simple, non-intrusive, and allow the employee to work more effectively. In some cases, these accommodations have been so intuitive and efficient that other employees have asked to have access to them! The accommodations described earlier for fatigue may also be helpful to address cognitive changes since the two are often intertwined. Many people use memory books or computer calendars (e.g., personal digital assistants) to help with memory problems. Some employees e-mail themselves to keep a “to do” list in their inboxes. Desktop computer programs such as Microsoft Outlook can help manage schedules, “to do” lists, and contact lists. These calendar programs can also be configured to send text messages from calendar entries to text pagers or cell phones that accept text messages. This allows the employee to put reminders into a computer calendar system and have those reminders sent to his or her text pager during the day. Structuring the work tasks to

maximize routine, minimize distractions, and to sequence work efforts to reduce the demands of multitasking may be helpful. Employers and employees with MS should begin by completing an analysis of the cognitive demands of the job, including interpersonal demands, before beginning the accommodation process.

Unpredictability of Symptoms

When planning accommodations in the workplace for people with MS, it is critical to consider the progression of MS. While the progression of limitations cannot be predicted, it makes sense when planning accommodations for current needs, to consider the future as well. Accommodations should also address episodic exacerbations where an employee may require a week of hospitalization or recovery from an exacerbation and perhaps a brief, graduated return to work.

Working and Living with MS

Most people with MS are of working age and either want to continue working or, if not currently at work, return to the workforce. Many people with MS do not have limitations that impact their employment. For those individuals who do have significant MS-related limitations affecting their employment, many can work successfully with reasonable accommodations that are typically minor in nature. With recent medical advances relating to MS and advances in awareness and

technology regarding job accommodations, MS will present fewer barriers to employment in the near future.

Resources

Assistive Technology Partners
601 E. 18th Avenue, Suite 130
Denver, CO 80203
303/315-1280 Main
800/255-3477 within Colorado
303/837-8964 TTY
303/837-1208 FAX
www.assistivetechologypartners.org

Colorado MS Society
700 Broadway, Suite 808
Denver, CO 80203-3442
303/831-0700 or 800/FIGHT-MS
303/831-8001 FAX
www.nationalmssociety.org

Job Accommodation Network (JAN)
West Virginia University
P.O. Box 6080
Morgantown, WV 26506-6080
800/526-7234
www.jan.wvu.edu

National Multiple Sclerosis Society
733 Third Avenue
New York, NY 10017
800/344-4867
www.nmss.org

President's Committee on
Employment of People with
Disabilities
202/376-6200
www.pcepd.gov

Rocky Mountain Disability and
Business Technical Assistance
Center

3630 Sinton Road, #103
Colorado Springs, CO 80907
800/949-4232 Voice/TTY
719/444-0269 FAX
www.ada-infonet.org

University of Washington National
Research and Training Center on
Multiple Sclerosis
www.msrrtc.washington.edu

U.S. Department of Justice
800/514-0301
www.usdoj.gov/crt/ada/adahom1.htm

U.S. Equal Employment Opportunity
Commission (EEOC)
800/669- EEOC Voice
800/800-3302 TTY
www.eeoc.gov

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