



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 approximately 400,000 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 35% are working. There are a number of reasons for this high unemployment rate, but it is clear that many people living 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 without apparent symptoms earlier in life and for which there is some 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 relapsing-remitting course becomes 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 blad-

ders 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. It is important to remember that, because most people living with MS have relapsing and remitting symptoms, an individual who experiences significant fatigue, vision changes, problems walking, or memory problems one week may have fewer problems once the exacerbation resolves. 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 him or herself 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 productively.

The American with Disabilities Act and Reasonable Accommodations

Title I of the Americans with Disabilities Act (ADA) protects qualified individuals with disabilities against discrimination on the basis of disability in all terms, conditions, and privileges of employment, including recruitment, pre-employment screening, hiring, benefits, promotions, layoff, and termination. The ADA defines disability as a physical or mental impairment that substantially limits a major life activity, and it specifically identifies the ability to see and to walk, the performance of manual tasks, and the normal operation of neurological functions, among other things, as major life activities.

In determining whether MS substantially limits one or more major life activities, mitigating measures are not considered. Thus, if an individual's MS is substantially controlled with medication, he or she could nevertheless qualify as an individual with a disability entitled to ADA protections. Furthermore, as long as a person's MS substantially limits a major life activity when active, its episodic nature will not prevent it from being classified as a disability.

Employers must reasonably accommodate qualified persons with disabilities so that they may perform the essential functions of jobs held or desired, but employers do not have to provide an accommodation if it would impose an undue hardship on the business. Successful accommodations are often minor, however, requiring little or no expense. Successful accommodations should 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. For others, fatigue may be a constant limitation. It is not unusual for individuals to report that their “best times” are in the morning and 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. Strate-

gies 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, and monitor height. 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 or auto-correct features 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 included as accessibility features in both Microsoft and Mac operating systems. 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 for the employee to change clothes, the 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 sensa-

tion, 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 to help with memory problems. Some employees email themselves reminders to keep a “to do” list in their inboxes. There are both PC, Mac, and web-based integrated calendar, task list, and email systems. These calendar programs can also be configured to alerts or emails to smart phones and other computers, and/or SMS text messages to mobile phones. This allows an employee to put reminders into a computer calendar system and have those reminders sent to his or her phone, or computer 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

National Multiple Sclerosis Society
www.nmss.org

Disability and Business Technical Assistance Centers 800.949.4232, www.adata.org

Job Accommodation Network
800.526.7234, www.askjan.org

University of Washington Rehabilitation Research and Training Center on Multiple Sclerosis
<http://msrrtc.washington.edu>

U.S. Department of Justice
202.514.2000
www.usdoj.gov/crt/ada/adahom1.htm

Equal Employment Opportunity Commission
For the nearest field office, call 800.669.4000 (voice), 800.669.6820 (TTY).
For publications on ADA employment issues, call 800.669.3362 (voice), 800.669.3302 (TTY).
For online information, www.eeoc.gov

Tech Act Projects in each state for information and referral with reference to assistive technologies.
<http://resnaprojects.org/nattap/scripts/nattap-contacts.pl>

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The Equal Employment Opportunity Commission has issued enforcement guidance which provides additional clarification of various elements of the Title I provisions under the ADA. Copies of the guidance documents are available for viewing and downloading from the EEOC web site at:
<http://www.eeoc.gov>

About this Brochure

This brochure is one of a series on human resources practices and workplace accommodations for persons with disabilities edited by Susanne M. Bruyère, Ph.D., CRC, Director, Employment and Disability Institute, Cornell University ILR School.

This brochure was developed in 2001 for Cornell University by Kurt L. Johnson, Ph.D., CRC., co-Principal Investigator for the University of Washington Rehabilitation Research and Training Center on Multiple Sclerosis. He reviewed and updated it in 2010. It received legal review in 2011 by Beth Reiter, an independent legal consultant, Ithaca, N.Y., with assistance from Sara Ferguson, a Cornell University Employment and Disability Institute student research assistant.

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The full text of this brochure, and others in this series, can be found at www.hrTips.org.

More information on accessibility and accommodation is available from the ADA National Network at 800.949.4232 (voice/ TTY), www.adata.org.

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