

January 2004

Family and Medical Leaves for Chronic Disease: Multiple Sclerosis

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Multiple sclerosis (MS) is a slowly progressive, lifelong chronic disease of the central nervous system. It is the most common cause of neurologic disability in young adults.

MS generally occurs in persons between 20-40 years of age. In high-risk areas, the incidence is about 1:1000 people; it is five times more common in temperate zones (such as the northern US) than in tropical areas. Women outnumber men at a ratio of 2:1; the gender ratio is more balanced among those who develop symptoms at a later age.

MS may elude an employer's understanding because its presentation can vary amongst different individuals. Its relation to an employee's need for FMLA leave is therefore hard to predict. The employer who is well informed on the nature of MS will be at an advantage if ever confronted with the need to manage FMLA leave for someone affected by the illness.

Information on MS has been excerpted from *The Medical Disability Advisor: Workplace Guidelines for Disability Duration*, Fourth Edition (MDA) guidelines. The MDA serves as an educational tool that helps administrators understand the significance *and* unpredictability of MS. The MDA couples general medical descriptions of various diagnoses with specific workplace-related information, enabling those who manage disability cases and/or administer FMLA leave to make educated decisions. Once we cover the medical facts of the disease, we will return to some concluding observations on the relation between FMLA and MS.

In MS, local areas of the fatty substance that surrounds and insulates nerve cell fibers in the brain and spinal cord (myelin) are destroyed. This demyelination can cause slowed or blocked nerve impulse conduction and occurs in random patches (plaques) at any site where "white matter" (nerves encased in myelin) occurs. New evidence suggests that nerve fiber loss may provide an explanation for some of the neurologic deficits experienced by many persons with MS.

Although the exact cause of MS is unknown, many believe it to be a condition in which the body's defense system reacts against its own tissue (autoimmune disease). Such attacks may be linked to unknown environmental triggers such as viruses. There may be a genetic factor, as first-degree relatives (parents, children and siblings) of those with MS have a 1-3% chance of getting the disease.

The following list of symptoms may accompany MS. Because it can disrupt function in any area of the central nervous system (CNS), symptoms are varied, numerous, and of differing severity and duration. Approximately 50% of individuals will present with visual problems (including blurred or double vision, red-green color distortion, loss of vision in one eye, or optic nerve inflammation called optic neuritis). Other common symptoms include severe fatigue, muscle weakness in extremities, numbness, tingling and loss of sensation (paresthesias), unsteady or abnormal limb movements and positioning, loss of coordination, loss of balance or equilibrium, prominent gait, impaired dexterity, urinary problems, disturbed speech patterns, mental disturbances, impaired thermal sensation, muscle stiffness and spasms, tremor, and dizziness.

Cognitive problems with attention span, concentration, memory, and judgment may be noted at any time during the course of the disease. Depression is common, and over the course of the disease 5-10% of the individuals with MS will develop overt psychiatric disorders such as manic-depression (bipolar) or paranoia. Symptoms can last from several days to weeks.

The employer should not presume that a diagnosis of MS is predictive of immediate or complete disability. MS can be characterized by a series of attacks followed by a period during which the symptoms of the disease lessen or disappear (complete or partial remission). After a period of stability, the next attack may not occur for several years and recur with new symptoms. In some persons, the disease progresses by gradual clinical decline with no distinct periods of remission. In females, relapses are common in the first 2-3 months following pregnancy. Diagnosis is often a considerable challenge because of the potential for an infinite array of signs and symptoms. After exclusion of all other causes, criteria for diagnosis must include at least two neurologic events separated in time by at least a month, occurring in more than one location within the central nervous system.

Search for a cure is still in progress. Treatment is designed to deal with acute exacerbations, modify the disease process, lessen the symptoms, and improve day-to-day lifestyle. Treatment is directed at modifying the course of the disease and primarily includes the use of anti-inflammatory (corticosteroids or beta-interferon) medications, procedures such as plasmapheresis that interfere with or suppress the body's immune response (immunosuppressants), or a combination of corticosteroid and immunosuppressant drugs. MS symptoms can be treated with drugs to address muscle weakness and spasticity, physical therapy to strengthen weakened muscles, and occupational therapy to teach individuals

how to deal with stress both in the workplace and at home. Treatment also targets bladder, bowel, and sexual dysfunction, and pain management. One of the most difficult aspects for the individual with MS is the sense of uncertainty about the course of the disease. Psychiatric or psychological counseling may be necessary to provide support.

Again, the prognosis is hard to predict, and it is unfair to underestimate or overestimate the level of disability the individual will experience. MS may progress rapidly, disabling the person by early adulthood or causing death within months of onset. However, the majority of young individuals with MS (70%) has a virtually normal life expectancy and can lead active and productive lives for years. The course of the disease and the rate of disability do, however, vary considerably from person to person. Some persons may have periods of acute exacerbation with prolonged full or partial remissions. While most individuals at least partially recover from the first attack, others gradually become more disabled, bedridden, and incontinent by early mid-life. A small group of individuals suffer gross disability within the first year. Although MS is not in itself fatal, those who are severely disabled may die from the complications of being bedridden or from recurrent infections.

Work restrictions and accommodations will often be required. In advanced cases of MS, the individual may require handicapped, ADA-compliant, accessible facilities. Other restrictions and accommodations will depend on the nature of the individual's job, and nature and severity of symptoms. The individual may require frequent rest periods or changes in work hours, start times, and length of the workday because of fatigue. Visual disturbances may also impact the ability to perform certain activities.

The variety of symptoms and the gradations of severity must be recognized from the outset. The symptoms can range from loss of vision to muscle spasms, from severe fatigue to dizziness. Similarly, the severity varies across individuals and across each individual's lifespan. An individual suffering from MS may remain nearly fully functional throughout a career. By contrast, an individual may require accommodations and modified duty work from the onset, only to deteriorate further to the point of being bedridden.

The process of responding accurately and respectfully to FMLA leave requests, then, requires sensitivity to the extremes posed by MS. Gaining further understanding of MS, while remaining mindful of basic FMLA tenets, will help you minimize the losses incurred by this disease—both losses to the employee and the company. As medical science improves the treatments for resisting the advance of MS, so should the workplace improve its ability to promote the productivity of those with MS, one of the initial steps being a clearer understanding of what may and may not be involved with a struggle against the disease.

In addition, as is consistent with FMLA leave, the affected party may be a parent, spouse or child of the employee. As a result, the predictability and severity of the illness are one further remove from the employer's view. Operating remotely, as it were, requires that the employer be even more keenly sensitive to the issues at hand.

What then is the role of FMLA leave in mitigating the effects of MS on the individual and the work place?

As a starting point for a response to this question, we must recognize that MS often steals people from the workplace: "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 living with MS would prefer to be working and could work productively with fairly minor accommodations in the workplace."¹

Among these "fairly minor accommodations" are two applications of FMLA leave.

The first is intermittent leave. From all that's been noted concerning MS, it is obvious that intermittent FMLA leave may be necessary—either for immediate relief from symptoms or as a response to the need for treatment or rehabilitation. The application of FMLA consistent with the individual symptomatology can extend the employee's productivity in the workplace.

The second is a reduced work schedule. This use of FMLA leave can be even more productive, being more proactive and supportive of the employee's rehabilitation. By applying a reduced work schedule to someone participating in FMLA leave, the employer will probably prolong the individual's ability to continue to perform the essential functions of his or her job and to improve quality of life.

If the employer negotiates with the employee the reduced work schedule (for example, a six-hour workday), stability may be gained and the need for intermittent leave reduced. The shorter day may preclude some of the fatigue and the concentration/memory issues that generally arise. It will help keep the person focused. Being "focused" is not only important for accomplishing tasks at work, but it is a habit of mind that may help minimize the issues of depressed mood.

An employee who knows there is an educated concern and an explicit plan for accommodating him or her will generally reciprocate the investment in the workplace.

¹ "Workplace Accommodations for People Living with Multiple Sclerosis"
http://www.ilr.cornell.edu/ped/hr_tips/article.cfm?b_id=15&view_all=true.

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