



MS Presents Special Challenges

Patients with multiple sclerosis have symptoms far more complex and subject to change than the typical SNF or assisted living resident.

SOME 10 PERCENT OF PEOPLE with multiple sclerosis (MS) enter a nursing facility or assisted living center at some point in their lives, according to estimates by the National Multiple Sclerosis Society. These individuals require targeted, specialized services that are comprehensive and incorporate a range of professional expertise.

Robert Buchanan, associate dean for research at the College of Health and Human Services, University of North Carolina at Charlotte, has conducted extensive studies comparing frail elderly nursing facility patients with MS patients through an analysis of the minimum data set. His findings indicate that patients with MS tend to be younger, more mentally alert, more physically dependent, present with more symptoms of depression, have stronger ties to the community, and have longer lengths of stay. Experience shows that 60 percent of nursing facility patients with MS are less than 60 years of age, compared with 10 to 12 percent of others in the facility.

These differences can create a huge divide in a patient population.

A Many-Faceted Disease

Nursing facility and assisted living staff serving patients and residents with MS require specialized knowledge of the disease and its management, as well as sensitivity to the emotional, cognitive, social, and family issues that are involved. Knowledge and training in these areas will help facility staff effectively manage clinical conditions presented in MS as well as contribute sig-

nificantly to the patient's physical functioning and quality of life.

Multiple sclerosis is an unpredictable neurological disease that is thought to be an autoimmune disease. Misguided immune cells attack the protective myelin that surrounds the nerve fibers in the central nervous system (brain,

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spinal cord, and optic nerve), as well as the nerve fibers themselves. These inflammatory attacks cause scarring at multiple sites (multiple sclerosis) in the central nervous system, and it is this damage to the myelin and nerve fibers that causes the symptoms of MS.

Symptoms of MS are wide-ranging and can include fatigue, spasticity, balance and gait problems, sensory disturbances, visual impairment, cognitive deficits, bowel and bladder dysfunction, tremor, numbness, pain, swallowing problems, and even complete paralysis. There can be great variability in symptoms for the person with MS, not only over a long period of time, but within the same day. These fluctuations and the overall sense of unpredictability and randomness present a great challenge to individuals with MS and their caregivers.

While some of the symptoms of MS

are seen in other disorders and may be familiar to staff, the severity, clustering, and nature of these symptoms present a unique challenge to caregivers and have implications for facilities in terms of management and operations.

Symptom Management

A brief review of MS symptoms as related to their clinical and management implications includes:

- **Fatigue.** One of the most common symptoms of MS is a lack of physical energy, mental energy, or both. Fatigue in MS can be overwhelming and can come and go over a period of hours. A patient may be able to accomplish tasks independently in the morning and require assistance later in the day. Therapies, activities, and meals may need to be scheduled with rest periods in between.

Overheating can make fatigue worse. MS patients may be able to ambulate at one time and require wheeled mobility at other times. Transfers may be different for the same patient, depending on his or her level of fatigue at the time. Staff must be sensitized to the fatigue issue so they do not interpret it as resistance or laziness.

- **Sensory disturbance.** Numbness and other sensory deficits can present safety concerns in terms of bathing and feeding (particularly in terms of exposure to hot water, beverages, and food).

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Patients with decreased sensation may not realize that they have hurt themselves and may need to be checked periodically to make sure there are no scrapes, cuts, or pressure-sensitive areas that could develop into pressure ulcers. In terms of bowel management, decreased sensation may cause a patient to feel uncertain as to complete elimination or may cause them to sit on a toilet for long periods without discomfort. Periodic reminders and checking of the patient is suggested.

■ **Spasticity** Involuntary spasms, as well as muscle stiffness, can affect mobility, transfers, and sleep and may cause significant discomfort. Spasticity is another symptom that can change over the course of a day or week. If spasticity is not managed, complications such as fatigue, severe pain, and contractures can occur. Because spasticity is involuntary, it is important for staff to remember that telling a patient to “relax” will likely make things worse. It is best to have the patient stop what he or she is doing and wait until the spasm passes. It is also important that quick, sudden movements be avoided as they can set off spasms. Moving slowly and smoothly, including stretching exercises that are slow, and holding positions for a longer period of time than traditional range-of-motion exercises, will be helpful.

Several medications, such as baclofen and tizanidine, are often very effective. Patients with spasticity who are ambulatory should be encouraged to use a cane or a walker. An unusual increase in spasticity may be indicative of a bladder infection.

■ **Tremor** Uncontrollable shaking is common in patients with MS. Many times it occurs only during physical movement, not when a person is at rest. The shaking becomes more pronounced as the person tries to grasp or reach for something and can be exaggerated with stress. It is important that providers strategically place handrails and grab bars to provide safe and independent mobility. Weights and other

devices can be attached to a limb, or to objects such as eating utensils, to compensate for tremors.

■ **Balance problems** These typically result in a swaying type of gait known as ataxia. Therapeutic exercises that challenge the patient’s balance may be helpful in stimulating balance centers. Attention to sitting balance is an important safety concern, especially when changing to a standing position or transferring to a wheelchair. Side trunk supports and seat belts—as positioning devices, not as restraints—are

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the best options for seating balance, as are power wheelchairs that “tilt.” Again, handrails and grab bars, as well as canes and walkers, are helpful in addressing balance issues.

■ **Weakness** Problems such as toe drag, foot drop, and gait abnormalities are characteristic signs of weakness in MS patients, as is weakness in the arms, which can significantly interfere with carrying out activities of daily living, particularly transfers. Use of mobility devices can offset the effects of weakness, particularly power chairs that have hand controls or other adaptive devices for mobilization. During transfers, a belt around a patient’s waist can improve safety and function by providing something to hold onto. Managing weakness must be done in conjunction with management of spasticity and fatigue to be effective.

■ **Vision deficits** Double vision, inflammation of the optic nerve (optic neuritis), involuntary eyeball move-

ment, and cataracts can occur and, as with many other MS symptoms, may increase with fatigue, stress, or high temperatures. Some patients with MS will qualify for services for the legally blind. The easiest reading material for patients with MS who are visually impaired is plain black lettering on white paper in at least a size 14 point font.

■ **Bladder dysfunction** Frequency or urgency of urination, hesitancy in starting urination, nocturia, and incontinence are common MS symptoms. Proper management is necessary to prevent urinary tract infections and dangerous urinary retention that may damage the detrusor (the primary bladder muscle).

Many people with MS have managed bladder issues for many years, including self-management of intermittent catheterization. For many, however, the need to urinate frequently or the experience of incontinence is discouraging and can cause them to withdraw socially due to embarrassment or fear of having an “accident.” Bathroom facilities placed conveniently near activity areas will make it easier for those dealing with bladder issues to participate in activity programs.

Some patients with MS report that cranberry extract in gel cap or tablet form is helpful in avoiding urinary tract infection. Patients who suffer from urgency or bladder spasms should avoid caffeinated and carbonated beverages. For some patients, indwelling catheters may be necessary. Bladder infections are a common complication for people with MS and, though “silent” in presentation, may cause a patient’s functional status to change.

■ **Bowel dysfunction** People with MS often suffer from constipation due to inadequate fluid or bulk in the diet, decreased physical activity, medications, or MS involvement that slows the bowel or weakens the abdominal muscles. Interventions include increasing fluid and fiber intake, keeping a

regular bowel movement schedule, bulk formers, stool softeners, oral stimulants, laxatives, and mechanical stimulation. Diarrhea may also occur secondary to fecal impaction after overuse of laxatives or medications.

Sensitivity to the patient who has had uninhibited bowel elimination is essential. A structured daily plan for bowel management can lead to more predictable bowel habits.

■ *Swallowing difficulties* People with MS may have difficulty swallowing, as well as a tendency toward choking. Changing the consistency of food and planning rest periods before meals may help prevent these problems and aid in adequate nutrition. If a patient takes a long time to eat, reheating food after 20 minutes can make it more palatable.

Staff will need to be patient when assisting patients with MS. Patients should refrain from talking while swal-

lowing, if possible, as choking often occurs when these two activities are simultaneous.

■ *Pain.* Neuropathic pain, which relates to sensory disturbances, is a common symptom in patients with MS. Postural problems may also cause significant back and neck pain that can be addressed with positioning strategies. Neuralgic facial pain is often mistaken as tooth pain. Traditional pain medications such as aspirin, ibuprofen, and codeine are usually ineffective in relieving pain associated with MS, but anticonvulsants such as carbamazepine and gabapentin are often helpful.

Cognitive And Emotional Issues

Specific cognitive deficits such as short-term memory loss, shortness of attention span, impaired judgment, difficulty finding words, and impaired planning and organizational skills are

common in MS. These often impact the ability to process information in a timely manner, learn new schedules, and generally adapt to changing situations. However, the intellect in persons with MS often remains intact, and patients are usually alert and oriented. But it is important to recognize that a patient's ability to self-report may be impaired. Cognitive status should be considered when patients are forgetful or confused. A patient's judgment, planning, and organizational function may impact his or her safety when operating wheeled mobility, particularly power chairs. Impaired cognition may mean that a patient does not report an injury that needs attention.

The adjustment to assisted living or nursing facility life for the person with MS is complicated by the ongoing grieving process that he or she is experiencing over the many losses that

accompany the disease—the loss of physical control over one’s body, the loss of an imagined life as a healthy individual, loss of work, and separation from family and community. Many are struggling with anger, fear, frustration, and depression. Staff may be the target of these feelings and need to be sensitive to the emotional status of these individuals. Caregivers need to be attentive to signs of depression, which is very common in MS, and they must be able to identify severe depression and risk of suicide. Due to the myriad losses that persons with MS have experienced, allowing patients with MS as much autonomy and choice as possible and encouraging them to participate in their own care will be particularly empowering.

Being younger than the geriatric population in the typical long term care setting, people with MS will gen-

erally have different needs and interests than other residents. Providing age-appropriate activities and making sure the environment is accessible are important and will promote socialization and independence.

Management Issues

Facilities serving people with MS should not accept functional decline as inevitable. Primary health care needs for this younger population must be addressed to ensure good preventive health, including such measures as mammograms, pap smears, and cholesterol screenings. Early detection of signs indicative of exacerbations, decline, or infection is very important. Climate control, stimulating age-appropriate activities, access to durable medical equipment, promotion of assistive technology (including access to computers), rehabilitation, and

accessible transportation will all contribute to the quality of life for patients with MS.

Upon initial diagnosis, people with MS often express their greatest fears as “needing to use a wheelchair” and “ending up in a nursing facility as the only young person.” Yet, with knowledge, sensitivity, and a commitment to this challenging population, facilities can enrich their communities and enhance the lives of those struggling with the devastating effects of MS. ■

For More Information

■ Providers may call the National Multiple Sclerosis Society’s Professional Resource Center at (866) 678-7328 to discuss strategies for dealing with specific cases. They may also e-mail HealthProf_info@nmss.org or consult the “professional” area on its Web site at www.nationalmssociety.org.