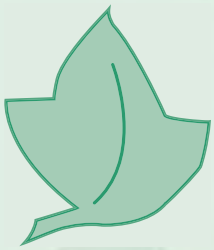
NATIONAL MULTIPLE SCLEROSIS SOCIETY

Assisted Living for Individuals with Multiple Sclerosis:

Guidelines & Recommendations



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The National Multiple Sclerosis Society . . . To end the devastating effects of MS.

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DISCLAIMER

The content of this document is based on best practices and clinical experience of health care professionals specializing in the care of people with multiple sclerosis. It is intended to provide a guide for serving people with MS in the assisted living home setting, but is not meant to substitute for, or to supersede, individualized physician treatment and advice.

Introduction

WHAT IS THIS DOCUMENT?

This document was developed by the National Multiple Sclerosis Society (NMSS) to provide guidance to administrators and staff of assisted living facilities that are seeking to develop effective service plans for residents with multiple sclerosis (MS). These guidelines address the unique set of clinical conditions of residents with MS and provide recommendations to maximize their quality of life.

The NMSS is a leader in the initiation, support, and promotion of quality and age-appropriate care options for people with MS. Consistent with this responsibility, the Society recently convened an expert panel of NMSS home office and chapter staff, MS specialists in the fields of medicine, nursing, social service, and long term care, and assisted living providers to identify the key components of care for residents with MS in assisted living facilities. This task force contributed knowledge and expertise to the preparation of this document through a series of meetings and research on best practices.

This document is designed to be a practical resource for administrators, clinical staff, and health care professionals involved in the direct care of assisted living residents with MS.

Important Note: *Because of the myriad of approaches, models and regulatory schemes found in assisted living across the country, some of the recommendations and guidelines presented here may be more relevant than others in your facility. Consider your state's regulations regarding assisted living care as you use this document. Particular attention should be paid to allowable health conditions, ambulation, transfer status of residents, and provision of medical care/ services in your state.*

Furthermore, this document will be used by a wide range of assisted living staff. Some may have an extensive clinical background, others social service expertise, and still others administrative, dietary, activities, or direct personal care experience. Therefore, the way this document is used will vary from reader to reader.

WHAT ARE OUR ASSUMPTIONS ABOUT ASSISTED LIVING?

Assisted living is intended to provide a residential environment and resident-centered services that foster residents' quality of life, right to privacy, choice, dignity, and independence. It is intended to provide quality services, individualized for residents and developed collaboratively with them, to support the resident's decision making to the maximum extent possible.

States generally regulate and monitor assisted living. Therefore, varying laws and regulations have created a diverse mix and fluid operating environment for providers and a mix of terminology, settings, and available services for consumers. For purposes of this document, an assisted living facility/community is assumed to provide, coordinate, or arrange the services listed below.

- 24-hour-awake staff to provide oversight and meet scheduled and unscheduled needs
- Provision and oversight of personal and supportive services (assistance with activities of daily living and instrumental activities of daily living)
- Coordination of supplemental personal care and medical services provided by home health care and community providers
- Provision or coordination of rehabilitation services
- Provision of health-related services (e.g., medication management services)
- Provision of social services
- Provision of recreational activities
- Provision of meals
- Provision of housekeeping and laundry services
- Provision or coordination of transportation services

WHAT IS MULTIPLE SCLEROSIS?

Multiple sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system (the brain and the spinal cord). Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or blindness. The progress, severity, and specific symptoms of MS in any one person cannot be predicted.

What Causes MS?

MS is thought to be an autoimmune disease, in which the body's own defense system attacks and damages myelin, the insulating material that surrounds and protects the

nerve fibers of the brain and spinal cord. This damage to the myelin and the nerve fibers forms hardened "plaques," and the scattered distribution of these hardened, or "sclerotic" areas throughout the brain and spinal cord gave rise to the name multiple sclerosis When any part of the myelin sheath or nerve fiber is damaged or destroyed, nerve impulses to and from the brain are distorted or interrupted, thereby causing the clinical manifestations. MS is not contagious and is not fatal, most affected individuals having normal or near-normal life expectancies.

What Are the Symptoms of MS?

The symptoms of MS may include tingling, numbness, painful sensations, slurred speech, and blurred or double vision. Some people experience muscle weakness, poor balance, poor coordination, muscle tightness or spasticity, or paralysis that may be temporary or permanent. Problems with bladder, bowel, or sexual function are common, and abnormal fatigue is often a major source of disability. MS can cause cognitive changes such as memory loss or difficulty concentrating, as well as mood swings and depression. Symptoms vary greatly in type and severity from one person to another and may come and go, particularly in the exacerbating-remitting form of the disease.

Who Gets MS?

An estimated 400,000 Americans have multiple sclerosis. Most are diagnosed between the ages of 20 and 50, and about two thirds are women. Studies indicate that genetic factors make certain individuals more susceptible to the disease, although MS is not an inherited disease in the usual sense.

What Are the General Patterns of MS?

MS is an unpredictable disease. Symptoms vary greatly from person to person, and may vary over time in the same person. Periods of active MS symptoms are called exacerbations, attacks, or relapses, and periods of recovery are called remissions. The disease ranges from very mild to intermittent to steadily progressive. Some people have few attacks and little if any cumulative disability over time. At diagnosis, most people have "relapsing-remitting" disease, with attacks, followed by periods of partial or total remission, which may last months or even years. Others experience a progressive disease course with steadily worsening symptoms. The disease may worsen steadily from the onset ("primary-progressive MS") or may become progressive after a relapsing-remitting course ("secondary-progressive MS"). Within the assisted living setting, most residents with MS will fall into the progressive category, most with a secondary progressive disease course.

Is It Easily Diagnosed?

MS is not always easy to detect or diagnose because symptoms may come and go, and other diseases of the central nervous system have some of the same symptoms. No single neurological or laboratory test can confirm or rule out MS. Recent advances in medical imaging, particularly MRI (magnetic resonance imaging), are helping to facilitate diagnosis. (A conclusive or definitive diagnosis requires evidence of many patches of scar tissue in different parts of the central nervous system, and at least two separate attacks of the disease. A definitive diagnosis can take several months. Sometimes it takes years.)

Can MS Be Cured?

No. The cause and the cure of MS are the subject of intensive worldwide research. The National MS Society funds some 220 research grants and fellowships each year and $100 million is spent annually by the National Institutes of Health on MS research. Knowledge about MS and other diseases of the central nervous system is growing quickly and many clinical trials are in progress.

Can MS Be Treated?

Yes, to a degree. Today, five medications approved by the Food & Drug Administration (FDA)—Avonex, Betaseron, Copaxone, Rebif, and Novantrone—reduce the frequency and severity of attacks of MS and may delay or slow down progression of MS. Many medications are available to reduce some of the symptoms of MS, and many other drug therapies are being clinically tested.

There are also many non-pharmacological ways to relieve particular MS symptoms. Physical therapy, exercise, vocational and cognitive rehabilitation, attention to diet, adequate rest, and counseling may be invaluable for maintaining independence and quality of life. Spasticity, bowel and urinary distress, pain, fatigue, depression, and other problems can be eased both with medication and with other therapy.

What Are the Long-Term Needs Generated by MS?

For those with progressive disability, there is increasing need for assistance with personal care and other activities of daily living. Progressive MS may result in difficult-to-manage bladder and bowel problems, significantly limited mobility, cognitive deficits, severe spasticity and tremors, and a high level of dependence with regard to activities of daily living. Social isolation is common, too, as ability to move about the community and social interactions diminish. Caregiver burnout, financial difficulties, emotional pain, and family distress also arise as outcomes of progressive disease. Cognitive changes may make it difficult for the individual to effectively manage his or her own care. The needs

that are generated by progressive MS can be met by a continuum of age-appropriate and accessible long-term care services including care management, home care, adult day programs, assisted living and other community-based housing options, and nursing home care.

RESIDENT PROFILE

Who Is the Typical Assisted Living Resident with MS?

Most commonly, assisted living provides relatively independent seniors with supervision, assistance, and limited health care services in an apartment-type setting. The typical resident in most assisted living programs is an 82-year-old woman who is mobile but who needs assistance with one or two personal activities. The typical length of stay is 24 months.

Young and middle-aged persons with disabilities have not yet widely used assisted living. However, these programs can bridge the gap for people with multiple sclerosis who are able to maintain a fairly high level of independence but who also need some assistance to meet the demands of the disease. These are individuals who do not require the comprehensive care provided through a full-scale medical program but who are able to choose community-based living that encourages self-determination and self-management, and provides support when needed.

Assisted living is also an option for individuals who are aging with disabilities and are looking to living options that can make life easier and promote continued independence. Therefore, assisted living meets an important need for a segment of the MS population.

The level of disability that is acceptable to any particular assisted living residence varies from state to state and from one facility to another. Thus, the admission criteria and criteria for continuing residency vary from state to state. For this reason, it is difficult to profile a typical resident. However, below are some needs of the likely assisted living resident with MS.

- ***Supervision to maximize safety.*** Safety concerns may arise when mobility problems, such as problems with balance, incoordination, and weakness increase the likelihood of falls or other injuries and accidents.
- ***Supervision due to cognitive deficits.*** Additional safety concerns may arise when cognitive deficits impair judgment, memory, ability to make good decisions, and ability to safely implement one's daily routine.
- ***Opportunities for socialization and involvement in a community.*** Individuals with MS who are living alone may suffer increased isolation as their disease worsens, especially if it has become more difficult to work or engage in volunteer pursuits. Concerns about falling, experiencing bowel or bladder accidents, cognitive changes, and issues regarding the accessibility of the home and community all contribute to social isolation.

- ***Assistance with activities of daily living.*** As we stress throughout this document, MS is very variable and individuals with the disease present with a wide range of needs for ADL assistance. Most typically, residents in assisted living residences with MS will be able to manage dressing, grooming, feeding, and toileting relatively independently or with minimal to moderate assistance. Some will likely be ambulatory, with or without an assistive device (cane, crutches, walker). Many will use a manual or power operated wheelchair, but they will generally be able to transfer independently or with minimal assistance and mobilize their wheeled mobility independently. This level of independence in transfers and mobility is frequently a requirement of the facility or of fire safety regulations in the state.

A challenging aspect of MS, which sets it apart from most other disorders encountered in the assisted care facility, is fluctuation in severity of impairment. In the relapsing-remitting form of MS, individuals may experience periods of new or worsened deficits, lasting days to weeks, or longer, with subsequent return to baseline, and in the progressive forms of MS, gradual worsening of deficits may occur over time. Each facility, along with the particular resident, must determine when care needs can no longer be adequately met by the resources of the facility and the community.

SECTION 2

Resident Life

ADMISSION AND ADJUSTMENT ISSUES

The decision to move away from one's home is always difficult. Even when remaining at home becomes impractical or impossible, the psychological ramifications of leaving all that is familiar provokes anxiety and discomfort. This is particularly true for people with MS and their families, as this is generally a younger population and a move of this sort is even more unexpected.

The adjustment to assisted living life for the person with MS is complicated by the ongoing grieving process over the many losses that accompany MS—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.

Staff members can help new residents to cope with the changes by:

- Encouraging expression of feelings
- Encouraging friendships with veteran residents
- Creating an atmosphere that is welcoming to the resident's family and friends
- Helping the resident stay connected to friends through phone calls and letters
- Encouraging the resident to continue to pursue former interests

Disclosure is a critical element in the admissions process. MS is often a progressive disease. Residents with MS may require more assistance than the typical assisted living resident, particularly during exacerbations of their disease. It is imperative that prospective residents are aware of the specific services that can be provided by the facility and what services must be obtained from community providers. They must be clear on all the costs that will be involved in order to meet their personal and clinical needs. They must also be clear about any specific criteria that might mandate discharge.

A "good fit" is integral in assuring a high quality of life for the resident. The needs of the resident must be consistent with the environment and services available at the facility. The "fit" should be reassessed periodically and open communication is imperative about when needs may exceed the facility's ability to meet them. There must be an honest and open dialogue at the time of the admission process and throughout the resident's stay at the facility. Establishing an open communication and problem-solving process at the beginning is critical to developing a successful, on-going resident-provider relationship.

EMOTIONAL ISSUES AND DEPRESSION

Certain emotional reactions are common to all chronic diseases, and these are experienced to some degree both by the person with the illness and by his/her family members. Common emotional reactions are fear, anger, depression, and guilt.

- Fear—of the unknown, of losing control over one's life
- Anger—at changes that are occurring
- Depression—feeling helpless and hopeless
- Guilt—the feeling of "letting others down," not being able to accomplish expected tasks

People with MS, as do those with other chronic illnesses, experience grief over the losses associated with their disease. MS affects the whole family. To live well with MS, families must be able to adjust to change—role change, financial change, and lifestyle alterations. Long before people with MS enter a facility, they and their families have had to make adjustments in many areas of their lives. This begins at the time they were diagnosed with MS, and continues throughout the unpredictable course of the disease. Each family member will have his or her own feelings about the situation, and each will have to adjust to the effects of MS.

Personal and social stability are severely affected by leaving one's home. An individual who moves to a facility may believe he/she has suffered irreversible loss, and will demonstrate grieving behavior. These emotional reactions may include anger, bitterness, depression, frustration, and poor self-esteem. Facility staff is frequently the target of angry feelings. It is important not to take these angry or unpleasant feelings personally. Some residents may place blame on family members or others for their situation. Faulting others may be an attempt to transform an otherwise inexplicable event into one that has an identifiable cause.

New residents may act in ways perceived to be self-centered and/or childish, or they may view staff members as existing only to satisfy their needs. Such a life change as leaving one's home may make the individual turn inward, leaving little energy to cultivate relationships or be attentive to other people's feelings. Residents may appear depressed and demoralized as they cope with the injured self-esteem that may accompany the move.

At least 50 percent of people with MS will experience a major depressive episode at some point over the disease course. Because of feelings of loss, as well as neurologic changes caused by the disease itself, depression is very common among persons with MS. Fatigue—which can be an outgrowth of depression or occur as a primary symptom—frequently compounds depression in persons with MS. Intervention with psychotherapy and/or antidepressants is usually effective. Local MS support groups may also be helpful.

In NMSS-supported studies on suicide and MS, researchers concluded that the level of disability is not the key predictor of suicide risk, since many people report feelings of satisfaction in spite of having chronic progressive disease. Rather, suicide risk was more related to a lack of connectedness with other people, and a negative self-perception of one's self, body, and one's future.

Symptoms of depression include: persistent sadness or unhappiness, lethargy, loss of interest in previously enjoyable activities, irritability, sudden change in appetite, disruption of normal sleep pattern, physical discomfort, difficulty thinking or concentrating, thoughts of suicide or death.

Warning signs of suicide risk include: talking about suicide, statements about hopelessness, helplessness, or worthlessness, preoccupation with death, suddenly happier, calmer, loss of interest in things one cares about, visiting or calling people one cares about, making arrangements, setting one's affairs in order, and giving things away.

TIPS: Depression

1. Staff should be attentive to signs of depression and offer referral to counseling, and pharmacologic treatment. Assisted living staff should be trained in identifying signs of severe depression and suicide risk.
2. Provide programs that support the spiritual life of residents. Living with the losses and disability of MS often precipitates serious existential questions about the meaning of the illness, fate, the existence of God, God's role in life events, life's unpredictability and injustices, values, priorities and more. Programs that support the spiritual life of residents are important in helping to grapple with these issues.
3. Support groups for MS residents outside of the facility may be helpful.
4. An opportunity for participation in local religious services is a plus.
5. Provide for permanent assignment of direct care staff as much as possible. This will facilitate specialized MS skills development in staff and foster meaningful, consistent relationships between staff and residents. Average length of stay in assisted living for the resident with MS may be considerably longer than the traditional geriatric resident.

CARE MANAGEMENT

Care management, that is, the coordination of medical and social services for the resident, may be offered directly by staff at the facility or may be arranged outside of the facility. Resources that may be useful in accessing care management include the National Multiple Sclerosis Society, home health agencies, private care managers, and other community-based social service agencies. The services of a care manager may be invaluable in identifying and arranging the array of services that are needed by the resident.

YOUNGER RESIDENTS

In a facility primarily oriented to elders, taking care of a young or middle-aged resident may pose unique stresses on the staff. Staff may be more likely to relate to the younger residents and may become over-involved. They may have feelings of self-identification with a young, severely impaired resident and think, "This might be me. . . . I've just had better luck." A resident may make sexual overtures to a staff member or may be the target of sexual overtures by staff. These complex relationship issues tend not to be anticipated in the elderly population. They should be anticipated with a younger population and addressed during staff training. Recognizing that these feelings of identification or involvement may interfere with the caregiving relationship and cause stress on the staff is the first step in preventing potential problems.

ACTIVITIES

While many assisted living programs do not have the resources to create new activity programs for younger residents, particularly if they are working with only a few, some modifications can be made to interest all age groups. Like seniors, residents with MS want access to activities that promote cognitive, physical, social, and emotional well being, and positive involvement in daily life. They want activities that reflect their needs, interests, functional levels, and abilities. A younger MS resident may want to shop in different stores, see a different movie, or spend time in a different section of a museum gallery than an elderly resident. Program offerings for younger residents should include community activities, wellness activities, discussion groups, as well as other intellectually stimulating pastimes, such as theater and museum outings. Accounting for varied interests is key for the provision of creative and enjoyable activities.

Educational, artistic, and cultural pursuits are essential for all residents' personal growth and well being. The entire assisted living resident community, regardless of age, benefits from access to libraries for reading materials and music. Connectivity to the community and the world outside the assisted living facility is of particularly high value to younger residents, fostered both by bringing outside resources in and by bringing residents to the outside sources.

Some assisted living facilities have adult day health programs on site. These programs may bring in other residents from the community as well as include facility residents. Programs like these offer an opportunity for socialization, stimulation, exercise and more.

TIPS: Activities

1. Offer age-appropriate and meaningful recreational, social, vocational and leisure activities for residents with MS. Activities might include:
   - continuing adult education
   - computer activities
   - volunteer opportunities or paid positions outside of the residence
   - theater trips
   - shopping trips
   - music and art activities
   - writing programs
   - pet therapy, or assisting in the care of an in-house pet
   - yoga, tai chi, and other movement therapies
   - current events discussion
   - guided imagery/meditation
   - cooking classes
   - support groups
   - participation in resident councils
2. Music and art therapies, writing programs, and pet therapy, etc. provide opportunities for self-expression. They may enhance adjustment to the assisted living setting, improve attitude and outlook and provide fun, stimulating activities for residents. The National MS Society may be able to provide referrals to expressive therapists who can design and/or conduct a program at the facility.
3. Work with community agencies and families to arrange for accessible transportation, discounted or free tickets to community events, volunteer opportunities in schools, homeless shelters, and other settings.
4. Trip planning requires careful consideration of accessibility and appropriateness of the travel requirements, physical plant of the destination (stairs, bathroom accommodations, etc.) and the number of individuals who will need to assist in order to ensure residents' safety, comfort, and enjoyment of the experience.
5. Day to day changes in MS symptoms, such as fatigue and cognitive impairments, may affect the MS resident's degree of general function and participation in activities. Always encourage the resident's involvement in decision making to the best of his/her ability.
6. Residents with MS also enjoy intergenerational activities such as Bingo, games, current events discussions, etc.
7. Encouraging a resident who is younger to "assist" with other residents can help them to feel more empowered and less isolated. They might be able to be called upon to visit a resident who is not feeling well, help an older resident use the computer, or be appointed as a resident advocate.
8. Computers are an important part of life for younger residents with MS. Access to the e-mail and Internet, whether in a central location, or through computer access in one's room, should be available.

SAFETY

In the assisted living environment, the safety of all residents must be maintained at all times. Provide orientation and training to management personnel and direct care staff on the specific safety risks/concerns that could potentially occur with residents with MS.

The primary safety issues for residents with MS derive from mobility problems. Problems with mobility—weakness, incoordination, problems with balance, spasticity—put an individual at an increased risk for falls and could potentially impede a resident's ability to safely perform daily personal care tasks.

Cognitive deficits and sensory deficits also place the resident at risk for accidents. MS deficits that are not effectively managed may lead the resident to feel unsafe, develop fear and anxiety that his/her care needs may not be fully met in the assisted living environment, or engender concern that he/she will be asked to leave the assisted living environment.

PRIVACY

Ideally, single rooms offer optimal privacy. When a private room is possible, the resident's room should be large enough to allow for visitors, and overnight visits from family members should be allowed. If the resident wants to entertain a group of friends, then the availability of a multi-purpose room for a scheduled gathering is important.

If a private room is not an option, consideration should be taken to match the MS resident with a roommate who is on an appropriate level cognitively and who is understanding of times when the resident may wish to spend time alone or with family.

Residents with MS may have young families who visit. Child-friendly (i.e., noise is acceptable, safe play areas) lounges or rooms where families/spouses can visit (and perhaps stay overnight) can help individuals with MS adjust more effectively to the assisted-living facility.

SCHEDULING

Flexible scheduling for meals is appealing to younger residents. Where elderly residents may appreciate a daily routine, younger residents may be more accustomed to having meals at various times of the day. If flexible meals and snacks are available in a country kitchen setting, this may prove to be inviting.

The scheduling of other ADL tasks is also important. The accessibility of facilities for toileting in the activity area, for example, may promote participation for a resident with MS who experiences incontinence or urgency. The possibility of social withdrawal is very real when independence is threatened or tainted by the issue of potentially embarrassing situations.

Residents with MS may experience MS fatigue mid-day and greatly benefit from a nap of an hour or two at this time. If possible, staff should facilitate this rest period and assist the resident to get back up for the evening.

Consider the availability of staff for assistance with showering, preparing snacks, medications, etc. The younger resident with MS is often heavier than an elderly resident and may require more staff assistance or time. The resident with MS may like to shower daily or several times a week and may require additional grooming assistance, such as hair drying or make-up application.

Physical needs will vary from person to person. However, it must be emphasized that the daily fluctuations of abilities will determine the extent of the physical needs of each individual.

ACCESSIBILITY

Physical disability and reliance on mobility devices requires special attention to accessibility of the environment. The growing interest in "universal design" (the design of buildings and environments that are accessible for everyone, regardless of disability, throughout the life span) will hopefully provide more barrier-free environments in the future.

While facilities with limited resources or older physical plants may not be able to eliminate barriers to accessibility, every effort should be made to maximize mobility, independence, and access within the facility.

Accessible design includes:

- Bathrooms with roll-in showers to accommodate the use of a shower wheelchair or transfer to a shower bench in order to maximize independence and reduce risk of injury
- Toilets that are of sufficient height to promote safe and efficient transfers from and to a wheelchair or from and to a standing or seated position
- Grab bars strategically placed to promote safe transfers from a wheelchair or efficient standing from a seated position
- Rooms large enough to have easy maneuverability for manual or electrically powered wheelchairs
- Wider halls and doors, barrier-free entrances, elevated electrical outlets, lowered switches, adjustable closet rods and shelves, adjustable counters, touch switches, lever handles, and other features are elements that promote an efficient and safe environment in which to live

Power Wheelchairs

Power wheelchairs used by many residents with MS are "hard" on the environment. Walls, doors, and elevators often sustain damage over time from these powerful, heavy wheelchairs scraping and colliding with them. There must be adequate space to maneuver and store large electrically powered wheelchairs, lifts and other equipment. Charging areas for power devices must be available.

Climate Control

Individually regulated heat and air-conditioning controls in resident rooms is a necessary environmental feature for residents with MS because most people with MS experience heat intolerance. The individual's symptoms may temporarily worsen when he or she is exposed to any hot environment, such as a hot room, hot and humid weather, hot showers or bath, or if they develop a fever.

Facilitating Socialization

The physical layout should encourage and support socialization and facilitate independence and mobility of residents, especially those with large wheelchairs

- Elevator controls that can be operated independently
- Accessible lounges and socialization areas to accommodate group exercise and recreation
- Wide corridors

Transportation

Accessible transportation is critical to engaging residents with MS in community activities. Lift access for all wheeled mobility should ideally be available in residence transport vehicles. However, if large power chairs are an issue, the use of a manual wheelchair, perhaps with an escort, might be a substitute on some community outings. Paratransit, your community's accessible transportation service for people with disabilities, should be explored and used as a supplement to the facility's transportation program. Resident's families who have a suitable van for transport may also be a resource and willing to help out for special occasions.

EQUIPMENT NEEDS

Many individuals with MS already have their own equipment and will bring it to the facility upon admission. However, repair and maintenance will be needed, and there may be times when new equipment is required, either as a replacement, or in response to a change in physical functioning.

Recognizing that many facilities may not have the resources to have a comprehensive and on-site equipment program, developing relationships with medical equipment vendors in the community who can consult as needed is recommended. However, identifying an in-house staff member with mechanical/technical skills to address uncomplicated mechanical problems will often lessen the need for outside maintenance.

Residents with MS who frequently use mobility equipment may tend to be "hard" on their equipment such as electrically powered wheelchairs because of symptoms such as tremors and spasticity. Thus, it may be necessary to provide frequent repairs in addition to regular maintenance. Many residents with MS are very dependent on their wheelchairs. These individuals may feel stranded and lost without them should they need to be taken off site for repairs and maintenance for any length of time.

Some residents may require power wheelchairs with specialized capabilities such as positioning devices (recliners), trunk supports, control devices such as joysticks, and other sophisticated systems. Proper positioning can improve comfort, independence, and mobility as well as prevent secondary complications such as skin breakdown, postural deformities/contractures, and compromised breathing.

Although the person with MS needs to be responsible for the care and maintenance of their own equipment, providing staff training concerning the appropriate use and cleaning of equipment, the proper functioning of urinary draining systems, the regular charging of electrically powered wheelchairs, and the proper wearing of such devices as splints and braces will help facilitate the longevity of the equipment. These activities may also prevent physical complications such as skin breakdown, increased spasticity, pain, joint contractures, bladder infections, and possible serious medical conditions.

ASSISTIVE TECHNOLOGY

Offering access to assistive technology for mobility, personal comfort, and intellectual stimulation will promote independence and increased self-worth for all residents. Assistive technology, e.g., power wheelchairs, adapted drive systems, computers, communication devices, etc., can be an aid to independence, foster personal comfort and provide intellectual engagement. Providing assistive technology can provide stimulation, counter isolation, promote self-sufficiency and control over the environment, enhance mental health, and reduce stress on staff by enabling the resident to perform tasks otherwise performed by personal care assistants and other staff.

The need for more specialized assistive technology often means the adaptation of the user interface, e.g., adding voice activation, providing magnification, installing larger, more manageable controls, or using non-manual, such as breath-controlled, switches for existing devices.

Personal comfort devices can include adapted emergency call systems, accessible bed controls, and modified controls for heating and air conditioning. Environmental control units (ECUs) are coordinated systems for controlling many aspects of the environment through a single device. ECUs can operate window shades, televisions, CD players, lights, phones, etc., all through one accessible control box. These units can enhance quality of life and reduce dependence on staff.

Intellectual engagement devices include technologies and software that facilitate access to the Internet, e-mail, and computer programs.

Environmental technology includes accessible/modified door openers and elevator call systems.

Clinical Issues

These guidelines for clinical and personal care, while specific to MS for our purpose here, may well apply to other assisted living residents. While some of the symptoms of MS are seen in other disorders and may be familiar to assisted living staff, the clustering, and nature of these symptoms present a unique challenge to the individual with MS and his/her caregivers. It is crucial that assisted living staff be aware of the unique ways these symptoms present in persons with MS, how they affect residents' day-to-day lives, and potential treatments and strategies for management.

MS SYMPTOM MANAGEMENT

The following symptoms of MS generate a wide variety of care needs. While not all of these symptoms will be present in any one individual, the nature of the disease is such that multiple symptoms will be present. Assisted living staff may meet many of the needs generated by these symptoms. Other needs may need to be met by supplemental services provided by a home care agency or other community providers. Access to appropriate health services and management of these symptoms are critical to avoiding clinical complications and preventing avoidable physical decline.

Balance Problems

Balance problems include an unsteady or "drunken" type of gait known as ataxia. Balance problems may lead to falls, general unsteadiness, and may pose safety risks especially when coming to a standing position or transferring to a wheelchair.

TIPS: Balance Problems

1. The resident may require close supervision during activities of daily living, especially in getting in and out of the shower and maneuvering around the kitchen and bathroom.
2. Handrails and grab bars strategically placed may provide safe and independent mobility and canes or walkers can help prevent falls for ambulatory residents.
3. Side trunk supports and seat belts (as positioning devices, not as restraints) are the best options for seating balance, as are wheelchairs with a "tilt" feature if balance issues are severe.
4. Supervised therapeutic exercises with a Swiss ball and other techniques that challenge balance may be helpful in stimulating balance centers and improving balance but other occupational and physical therapy measures may be necessary.

Bladder Dysfunction

Urinary bladder dysfunction is very common in MS and may occur in several forms. These include frequency and/or urgency of urination, incontinence, hesitancy in starting urine flow or, in some cases, complete inability to urinate (retention). Frequent nighttime urination (nocturia) may interfere with sleep, which may increase daytime fatigue. Proper management is necessary to prevent urinary tract infections, dangerous urinary retention that may damage the detrusor (the primary bladder muscle) and damage to kidneys due to back-up of urine into the kidney. The need to urinate frequently or incontinence is discouraging to an individual with MS and he/she may withdraw socially due to embarrassment or fear of having an accident.

Clinical Note: Medications such as oxybutin (Ditropan XL), tolteradine (Detrol), as well as other medications that relax the detrusor or bladder muscle and relieve symptoms of urgency and frequency, may be helpful. The major side effects of these medications are dry mouth and constipation, which will, in turn, need to be managed. In some residents, an indwelling catheter may be necessary to maintain independence and quality of life.

Many people with MS have managed bladder issues for many years. Intermittent catheterization is a common intervention, depending on the type of dysfunction. Self-management of intermittent catheterization is often a component of independent living for this population.

(see TIPS for dealing with bladder dysfunction on next page)

TIPS: Bladder Dysfunction

1. Some residents report that cranberry extract in gel cap or tablet form or cranberry juice is helpful for prevention of recurrent urinary tract infection.
2. Residents who suffer from urgency and/or bladder spasms should avoid caffeinated and carbonated beverages.
3. Residents should NOT necessarily sip fluids all day to remain hydrated. They should try to drink most of their fluids with their meals and go to the toilet 60–90 minutes later. A practical intake volume is approximately six 8-ounce glasses of fluid per day. This is based on anecdotal experience.
4. Bathroom facilities placed conveniently near activity areas will make it easier for those dealing with bladder issues to participate in activity programs.
5. Residents who leak urine should wear appropriate protection. If leaking urine becomes excessive, a urologic assessment may be indicated.
6. There are many types of leg bags and even a "belly bag" which can be worn by residents with indwelling catheters. These are not visible to others and thus, will not interfere as much with social activities.
7. Some individuals with MS may elect surgical procedures to manage incontinence.

Bowel Dysfunction

People with MS may experience constipation because of inadequate fluid or bulk in the diet, decreased physical activity, medications, and/or MS involvement that may slow the bowel or weaken abdominal muscles. Interventions include increasing fluid and fiber intake, a routine bowel schedule, bulk formers, stool softeners, oral stimulants, laxatives, and mechanical stimulation. Frequent use of enemas should be avoided but may be necessary for optimal scheduling of activities and may also be the preference of the resident. Residents may have decreased rectal sensation, causing the resident to feel uncertainty as to complete elimination. Incomplete elimination may lead to fecal impaction. Incontinence of stool may occur in some individuals.

Diarrhea may occur secondary to fecal impaction, overuse of laxatives, or medications. Incontinence is much more likely to be a problem when diarrhea is present. An additional complication from diarrhea may be skin irritation and ambulation safety issues due to the nature of the "emergency". Sensitivity to the resident who has had uninhibited bowel elimination is essential. A structured, daily plan for bowel management can lead to more predictable bowel habits.

TIPS: Bowel Dysfunction

1. Because of constipation and decreased rectal sensation, some persons may sit on a toilet for excessively long periods. Periodic reminders and checking of the resident is suggested.

Cognitive Changes

Persons with MS may experience a range of cognitive problems and when present, these deficits may range from quite mild to severe. However rarely will an individual with MS present with global dementia or disorientation. 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. Additionally, MS may affect the ability to process information in a timely manner and generally adapt to changing situations. These cognitive impairments may bring a person with MS to assisted living, even if his/her physical disability is minimal. These residents may isolate themselves because they can no longer "keep up". In general, intellect in persons with MS who have cognitive changes remains intact.

TIPS: Cognitive Changes

1. Provide training to nursing and direct care staff in recognizing and responding to residents with cognitive deficits. Sensitivity and awareness of the cognitive and emotional issues that may influence the behavior of the resident can help staff manage behaviors more effectively.
2. Include training to staff in differentiating the cognitive deficits associated with MS from those associated with Alzheimer's disease and related dementias.
3. Recognize that a resident's ability to self-report may be impaired
4. Organize the environment so that items used regularly remain in familiar places.
5. Develop consistent daily routines.
6. Plan activities requiring mental effort early in the day, and limit them to a short time period.
7. Repeat information and write down important points. Follow verbal instructions with written back up and visual aids when possible. Encourage the person to keep a notebook, electronic organizer, or calendar to track important information.
8. Consider cognitive status when arranging purchase of a wheelchair. A resident's judgment, planning and organizational function may have an impact on the safety of operating even manual, but especially power-operated wheelchairs/scooters.
9. A neuropsychology consult can be useful to define the cognitive dysfunction and work with staff and the resident to compensate for it.

Dysphagia (Swallowing Difficulties)

While swallowing is not a problem for most people with MS, a few may experience difficulty swallowing or be prone to choking. Changing the consistency of food and planning rest periods before meals may help prevent possible choking and aid in adequate nutrition.

Clinical Note: Swallowing studies (barium swallow) are available as an outpatient procedure at most hospitals. They are best done in conjunction with the speech/language pathology service at the hospital to determine the exact nature of the resident's swallowing problems. Medical interventions to address swallowing problems include swallowing therapy, usually performed by a speech and language pathologist, and, in some situations, a surgically placed feeding tube (PEG—percutaneous endoscopic gastrostomy) may help to maintain fluid intake and nutrition.

TIPS: Dysphagia

1. Thickened tea and coffee are much more palatable when served iced than when warm. Such iced drinks resemble a milkshake in texture and taste.
2. Always add the thickener just before serving the liquid since it becomes too thick when it stands for any length of time.
3. Save some frozen drink containers from local fast food restaurants and ice cream shops for serving thickened juices. The presentation helps the palatability since we "expect" such drinks to be "thick" and "slushy."
4. If there is a microwave handy, reheat food after 20 minutes to make it more palatable.
5. Teach direct care staff how to perform the Heimlich maneuver on residents both confined and non-confined to a wheelchair. Residents identified with swallowing problems should be instructed in the self-Heimlich procedure.
6. Encourage the resident to refrain from talking while swallowing. Choking often occurs when these two activities are simultaneous.

Fatigue

Fatigue is one of the most common symptoms of MS. MS fatigue is a lack of physical energy, mental energy or both. People with MS may experience normal fatigue, fatigue of depression, the fatigue of disease, and/or the fatigue of neuromuscular overuse. Unlike fatigue experienced by neurologically normal individuals, fatigue in MS can be overwhelming and truly disabling. Like other MS symptoms, it may come and go over a period of hours or days. A resident may be able to accomplish tasks independently in the early part of the day and require assistance with those same tasks in the afternoon due to MS fatigue. Additionally, fatigue in MS may worsen dramatically in the presence of concurrent illness, especially if fever is present, or sometimes by exposure to heat, as in taking a hot shower, using a hot tub or heated swimming pool, or even sleeping under an electric blanket.

Clinical Note: Appropriate medications for the overwhelming lassitude of fatigue include amantadine, fluoxetine, or methylphenidate. A newer approach includes use of modafinil, a drug approved for the treatment of narcolepsy.

TIPS: Fatigue

1. A sudden increase in fatigue level is often the first sign of infection in residents with MS. Always monitor the resident's temperature when there is a sudden onset of fatigue. If the resident has a history of urinary tract infections, it is advisable to obtain a urinalysis as soon as possible following an increase in fatigue.
2. Overheating should be avoided to minimize fatigue in heat-sensitive individuals.
3. Encourage the resident to schedule therapy and activities and meals with rest periods in between.
4. Consult with an occupational therapist to discuss principles of energy conservation and specific energy saving techniques.
5. Meditation and other relaxation techniques may be useful in managing fatigue.
6. Provide most nutrition through the morning and noontime meals. Some residents with MS may be too tired in the evening to eat a hearty meal. Residents may wish to have a light meal self-prepared. This activity may provide an enhanced sense of well being which promotes independence. Otherwise, encourage attendance at meals in the dining room, which fosters socialization.
7. Fatigue can have a tremendous impact on the ability to carry out activities of daily living. Direct care staff must be aware that the resident may be independent in the morning, and require a great deal of assistance by the afternoon.
8. Do not make bath water too hot. It can cause both fatigue and weakness. Use of heated therapeutic pools may have similar effects.
9. Plan with the resident—spread out activities and tasks throughout the day.

Hearing Loss

Hearing loss is an uncommon symptom of MS. About 6% of people who have MS complain of impaired hearing. In very rare cases, hearing loss has been reported as the first symptom of the disease. Deafness due to MS is exceedingly rare, and most acute episodes of hearing loss caused by MS tend to improve. Hearing loss is usually associated with other symptoms that suggest damage to the brainstem—that part of the nervous system that contains the nerves that help to control vision, hearing, balance, and equilibrium. Because hearing deficits are so uncommon in MS, people with MS who do develop hearing loss should have their hearing thoroughly evaluated to rule out other causes.

Hypophonia (Decreased Voice Volume)

As MS progresses, some people may develop difficulty in volume control of their voice. These symptoms may become more pronounced if the resident is experiencing an exacerbation or is fatigued.

Clinical Note: Speech/language therapy may be effective in improving volume as well as other speech problems. Also, speech and language pathologists may be able to recommend assistive devices to aid communication.

Paresthesia (Sensory Disturbances)

The term paresthesia refers to tingling, burning, or other unusual skin sensations. Some residents with MS may experience hypersensitivity to touch or distorted sensations in response to touch. Sometimes ordinary touch or brushing of the skin may be painful. Many residents with MS experience an electric shock sensation upon flexion of the neck called, L'hermitte's phenomenon. Diminished sensation may present a safety concern in bathing and feeding (exposure to hot water, beverages, and food), smoking and use of ambulatory aides, and loss of sensation or discomfort to touch may affect a resident's intimacy in sexual activity.

Clinical Note: Medication, including some anticonvulsants, non-narcotic analgesics, and topical anesthetics may help these symptoms.

TIPS: Paresthesia

1. Some residents with MS may experience burning or stinging sensations on their legs and feet that may lead them to prefer to be barefoot or wear slippers rather than shoes and socks, and may worsen with weight bearing, leading them to prefer a wheel chair over walking Light foot massage with topical anesthetics may provide temporary relief, as do ice packs at times.
2. Reassure the resident and try distraction with socialization rather than allowing isolation from activities. Be aware that sensory symptoms can be painful.
3. Residents with decreased sensation and mobility impairments need to check themselves for scrapes and cuts and redness over pressure-sensitive areas as this may be a warning of a potential pressure sore.

Respiratory Muscle Weakness

Weakness of the respiratory muscles due to MS predisposes patients to pulmonary infections. Residents should be encouraged to receive both the influenza vaccine annually and the pneumovax (every 7–10 years). While a simple cold may not pose a problem to most people, the presence of respiratory muscle weakness and inadequate deep breathing and cough increase the risk of developing pneumonia. Residents are encouraged to focus on deep breathing exercises.

Seizures

Seizures occur only in about five percent of patients with MS and usually respond to anti-convulsant medications.

Spasticity

Spasticity (muscle stiffness, tightness, or involuntary muscle contractions) is one of the most challenging of all MS symptoms. Spasticity of the legs affects mobility and may cause significant discomfort. As with many MS symptoms, it is experienced differently by different people and can change over the course of the day or week within one person.

Management of spasticity may include stretching programs and prescription of antispasticity medication. Reduction of spasticity with these measures may reduce complications such as increased fatigue, and pain, as well as serious problems, such as skin breakdown and contractures.

Clinical Note: Medicines used to reduce spasticity include baclofen, diazepam, dantrolene sodium, and tizanidine. If a resident is having serious problems with spasticity, there are medical interventions that can be considered such as an implantable pump that delivers a drug called baclofen directly into the spinal column, botulinum toxin injections to relax muscles, or phenol blocks, which reduces stimulation of the muscle.

TIPS: Spasticity

1. Remember that muscle spasms are involuntary. Telling the resident to "relax" will not help and may even make things worse, since spasticity is often aggravated by anxiety. It is best to have the resident stop whatever they are doing if possible, and wait until the spasm passes before proceeding.
2. Avoid quick, sudden movements that can set off spasms. Guide the resident to move slowly and smoothly.
3. Stretching is different from the passive range of motion that is taught to direct care staff in their basic training. It is slower and positions are held longer. It is advisable to have a qualified medical professional (physical therapist) train a few direct care staff to facilitate these stretching exercises with residents, if this is allowable in your state. A typical maintenance schedule is 20 minutes three times a week. The stretching exercise program can be self-directed. It is preferable to perform stretching on a physical therapy mat for maximum stretch.
4. A few stretching exercises before getting out of bed can often aide the resident in safer and more efficient performance of ADLs (activities of daily living).
5. Residents with spasticity who are ambulatory should be encouraged to use a cane or walker to help stabilize balance in walking and transfers.
6. Correct positioning may decrease spasticity. A physical therapist can train residents and resident assistants in the best positioning techniques to control spasticity.
7. An unusual increase in spasticity may be indicative of a bladder infection.

Tremor

Tremor, or involuntary shaking, is common in MS and may be disabling when it affects the limbs or head. Tremor which appears with use of a limb is referred to as intention tremor or action tremor and may greatly impair functions such as reaching or grasping or placement of a foot in standing or walking. This is the most common and generally most disabling form of tremor that occurs in people with MS. Like spasticity, tremor may worsen with stress. A form of tremor referred to as postural tremor occurs when a limb or the whole body is being supported against gravity. A person who has a postural tremor will shake while sitting or standing, but not while lying down.

Clinical Note: Drugs such as hydroxyzine, clonazepam, propranolol, primidone, and isoniazide may help reduce tremor. Physical techniques, e.g., weighting, immobilization, and patterning may also help. Tremors are very challenging to control. Speech therapy may help control tremors of the lips, tongue, and jaw.

TIPS: Tremor

1. Handrails and grab bars strategically placed may provide safe and independent mobility.
2. Weights and other devices can be attached to a limb to inhibit or compensate for tremors. An occupational therapist is the health professional that can best advise about assistive devices to aid in the management of tremor.

Vision Deficits

MS may affect vision in several ways. Abnormalities in activation of muscles that move the eyes may result in double vision. Malfunction in the brain centers, which control eye movement, may also result in jerking movements of the eyes, known as nystagmus. Damage and inflammation to the optic nerves themselves, known as optic neuritis, results in varying degrees of visual loss, ranging from clouding or dimming of vision to, in some cases, severe visual loss. Cataracts may develop at a younger age in persons with MS because treatment with corticosteroid medications may promote their development. As with other MS symptoms, visual disturbances may increase with fatigue, stress, and high temperatures. Some residents may benefit from a consultation with an ophthalmologist or low vision center, though loss due to optic nerve damage, unlike ordinary visual impairment due to changes in the lens of the eye, are not correctable with lenses.

TIPS: Vision Deficits

1. Many residents with MS require large screen TV sets on tables that can be wheeled close to their sitting position.
2. Some MS residents qualify for services for the legally blind such as large print books, talking book players, and free rental of talking books that are mailed directly to the assisted living residence or individual resident.
3. The easiest written material for residents with visual impairment due to their MS is plain black lettering on white paper in at least a size 14 font.
4. Contrasting colors on doorframes will assist residents with MS to enter and exit rooms in their power operated wheelchairs and scooters with fewer collisions.
5. Direct care staff making periodic rounds can provide helpful assistance, i.e., reading the TV schedule and checking with the resident of a timed event.

Weakness

Muscle weakness is a common symptom of MS. Weakness can cause problems such as toe drag, foot drop, or other gait abnormalities. Weakness in the arms may cause problems in carrying out activities of daily living.

Weakness may result from disuse or from interrupted neurotransmission. Strengthening exercises may improve the strength of muscles weak from disuse but will not improve muscle weakness secondary to poor neurotransmission. Managing weakness must be done in conjunction with management of spasticity and fatigue to be effective.

TIPS: Weakness

1. Use of mobility devices may offset the effects of weakness. Residents should be encouraged to use mobility aids such as canes, crutches, or wheelchairs when necessary to preserve independence.
2. There is a proper and safe technique for using mobility aids. They need to be the appropriate height and size for an individual. Proper adjustments should be made by a physical therapist.
3. Wheelchairs may have removable arm and leg rests to improve safety and independence in transferring. Power-operated wheelchairs may have hand controls or other adaptive devices for mobilization.
4. Power-wheelchair batteries need to be recharged every evening.
5. A physical therapist can demonstrate various transfer techniques, such as stand and pivot and sliding boards, and determine which technique is most appropriate for the individual.
6. Wheelchairs should always be in a locked position before transferring.
7. Proper body mechanics (bent knees and straight back, legs widely placed) should be used when assisting residents.
8. A belt around the resident's waist can improve safety and function by providing something to hold on to during a transfer.

POTENTIAL CLINICAL COMPLICATIONS ASSOCIATED WITH MS

The following complications may arise in residents with MS:

Bladder Infection

Bladder infection is a very common occurrence in people with MS. Bladder infections may result in fever and "pseudo-exacerbations". These infections are often "silent" in presentation, but may cause a resident's functional status to change. Adequate fluids and cranberry tablets may be useful in preventing infection.

Clinical Note: Urinary tract infections are usually successfully treated with antibiotics. Prophylactic antibiotics are sometimes prescribed to prevent infection. Urinary retention should be ruled out by catheterization or bladder scanner. Frequent infection may indicate urinary retention or bladder stones.

Pressure Ulcers (Bed Sores)

Pressure ulcers in sedentary persons are not uncommon. Alteration in skin integrity and the development of pressure ulcers is a major concern of all long-term care facilities. The ambulatory resident is generally at low risk. The non-ambulatory resident with MS may be at high risk. In addition to the obvious risk due to decreased mobility, there are those situations associated with involuntary movements or spasms (causing skin shear), impaired sensory awareness (residents may not realize that they have just burned their finger, scraped a knee or need to be repositioned) and, impaired cognition (may forget to report an injury).

If the resident is using a manual wheelchair or a power operated wheelchair, the most effective prevention devices are a properly designed wheelchair that provides adequate positioning support and a pressure-relieving seat cushion. These work in two different ways. A properly fitted wheelchair and cushion are more comfortable, and provide fewer areas of pressure. Such wheelchairs may also be fitted with a tilt device that allows the resident to redistribute their weight by frequently tilting the chair into slightly different positions. Obtaining a proper fit in a wheelchair and recommendation for a proper cushion may require that the facility locate a seating consultant in the area. An appropriate mattress that has a shearless cover and pressure relief in heel and sacral areas is also critical for these residents who require additional support to prevent skin breakdown.

(see TIPS for dealing with pressure ulcers on next page)

TIPS: Pressure Ulcers

1. A weekly head to toe skin check by a direct care staff member in the vulnerable resident population will reduce the number of early pressure areas that progress to ulcers that are more significant.
2. Keep reminding staff and residents not to layer sheepskins, draw sheets and multiple incontinence pads under the resident, which decreases the effectiveness of the mattress (also true for wheelchair pads). The fewer layers, the better.
3. As with all residents, when the resident gets sick, their risk factors intensify. At these times, encourage increased frequency of repositioning and skin checks.

Pseudo-exacerbation

Residents with symptoms of new weakness, confusion, and decreased functional independence may be suffering from a flare-up of their MS. However, an acute infection, especially with fever, may result in sometimes dramatic worsening of symptoms. Before a diagnosis of exacerbation of MS is made, therefore, pulmonary or bladder infection, medication reaction, or other acute illness should be ruled out.

Long-Term Use of Steroids

Long-term or repeated steroid use (which is not usually recommended but may be in some residents' medical history) may result in a number of complications such as: cataracts, osteoporosis and, rarely, aseptic necrosis of the hip. Yearly bone density examination and monitoring by a physician is recommended.

Pain

Pain in MS is not uncommon. Pain caused by injury to nerve pathways in the central nervous system is called neuropathic pain and most commonly takes the form of burning, aching or tight sensations in limbs, trunk or even in the face. Neuropathic pain is usually constant and unrelated to activity or posture, which may distinguish it from pain of "pinched nerves" or orthopedic problems, which are usually aggravated or relieved by specific movements or positions. Trigeminal neuralgia, or tic doloreaux, is a specific type of pain which is usually severe, is localized to one side of the face, and occurs in jolts, likened by many to electrical shocks. Because its distribution may include the teeth, this type of pain is often mistaken for a dental pain. Low back pain and neck pain are often the result of abnormalities of posture, caused by weakness of muscles or abnormalities of gait. Gait problems may also cause or aggravate pain in the hips, knees or ankles and feet.

Clinical Note: Antispasticity drugs, anti-convulsants, anti-depressants, and opioids are used to treat neuropathic pain, including trigeminal neuralgia, and anti-inflammatory drugs and opioid or non-opioid analgesics are used to treat neck, back and joint pains. Intractable pain may require more invasive methods, such as implantation of pumps to deliver narcotic or antispasticity drugs into the spinal cord. Alternative pain therapies such as acupuncture, ultrasound, and meditation may be effective. Chronic pain management is a challenging area for staff development and nursing research. Guidelines for management of chronic pain are equally useful for MS residents as they are for all other populations affected.

TIPS: Pain

1. The pain of trigeminal neuralgia is often mistaken for "tooth" pain. The resident may state that they feel like they have a tooth abscess and may be decreasing solid food and fluid intake because it hurts to chew or even open the mouth to speak. Medications may relieve this pain, but surgical treatments are occasionally required if medications do not provide adequate relief or are not tolerated.
2. Traditional pain medications such as aspirin, ibuprofen, and codeine are usually ineffective in relieving neuropathic pain associated with MS but may be helpful in reducing back pain or joint pains.
3. The light pressure of a glove or stocking may ease the burning or tingling in a hand or leg.
4. Range of motion exercises and stretching tight muscles may ease the discomfort caused by immobility. Direct care assistants may supervise or assist with these as allowable in your state.

Side Effects from Disease Modifying Medications

In patients using one of the interferon medications (Avonex, Betaseron, or Rebif), there can be flu-like symptoms, and spasticity can be aggravated and sometimes even be mistaken for a relapse. Flu-like side effects are managed by reducing the dose, then titrating upward as symptoms subside. Also, non-steroidal anti-inflammatory drugs (NSAIDs) may control these flu-like symptoms. If side effects are intolerable, the resident might be switched to glatiramer acetate (Copaxone®), which is not an interferon. Injection site reactions may occur with all injectables and need to be monitored.

TIP: Side Effects from Disease Modifying Medications

1. Call the manufacturer of the drug to provide your staff with their training materials. Some manufacturers run support groups for people taking the drug, which are helpful and provide socialization.

PRIMARY HEALTH CARE NEEDS

Issues that relate to good general health and wellness are often neglected in persons with MS. Symptoms that stem from a non-MS cause are often brushed aside as "just another manifestation of MS." Health concerns of younger residents, e.g., menopause, may not be adequately addressed. Furthermore, some illnesses, most notably infections and other causes of fever, may affect individuals with MS in a unique way.

Residents with MS should adhere to the health-screening schedule recommended for all adults:

- Cholesterol once under age 50 and every 5 years over age 50
- Fecal blood annually over age 50
- Sigmoidoscopy every 5–10 years over age 50
- Clinical breast examination annually over age 40
- Mammography every 1–2 years over age 50
- Vision exam annually over age 65
- Hearing exam every 5 years over age 50
- Direct rectal exam (DRE) for prostate and colorectal cancers annually over age 40
- Prostate-specific antigen (PSA) blood test annually for men over 50
- PAP smear/gynecological exam annually (based on history and risk)
- Bone density testing (baseline by age 60–65, but younger in high risk individuals, such as those with MS)

Health screenings, such as mammography, are very important, particularly for this younger population, and may not be routinely provided to assisted living residents. Difficulty positioning someone with impaired posture for a mammogram may lead to inattention to this and other important preventive health measures. Neither disability, nor the need for escort service and/or specialized transportation, should defer these screening procedures.

In the general care of residents with MS, health care providers should consider:

- ***Menstrual Cycle:*** Sometimes symptoms such as fatigue, numbness, and neuropathic pain may increase in residents with MS just before menses and improve as the flow begins.
- ***Menopause:*** In women with MS, as with other women, menopause can cause uncomfortable symptoms. These have been controlled for some with hormone replacement therapy. Estrogen may be especially helpful in preventing osteoporosis for women with MS who are already at increased risk due to inactivity and steroid use. Recent studies have offered a new perspective on hormone replacement therapy and the risks and benefits of such therapy should be discussed carefully with the resident.
- ***Heat and Humidity:*** Heat aggravates MS symptoms in about 80 percent of people who have MS. This temporary worsening of symptoms, which can be relieved by cooling, should not be confused with disease worsening. Air conditioning is imperative for these residents. If a resident with MS must share a room with a geriatric resident, control of temperature needs to be addressed. Cold drinks and cool showers and ice packs/cooling vests may also help susceptible residents.
- ***Osteoporosis:*** Long-term use of corticosteroids may result in osteoporosis, which may reduce mobility over the long term. Physical inactivity may also promote osteoporosis. All residents with MS should be considered at risk for osteoporosis. Treatment and prevention with calcium-rich foods and dietary supplements (including Vitamin D) as well as with osteoporosis medication is likely to be indicated. Particular care in transfers and prevention of falls is very important as fractures may occur easily and heal slowly in this population.
- ***Exercise:*** Some residents note worsening symptoms, weakness, or even blurring of vision with exercise. Cooling strategies can alleviate these changes, caused by the temporary elevation in core body temperature. Avoid being over-zealous in organized exercise programs.
- ***Infections:*** While infections, such as urinary tract infections or flu, can precipitate acute attacks of MS, they may also produce fevers that temporarily worsen existing symptoms. This type of pseudo-exacerbation will subside as the fever subsides. Symptoms that occur in the presence of a fever should be carefully assessed to determine whether they are indicative of a true attack that should be treated.

- ***Hypothyroidism:*** This condition can cause slowing down, fatigue, weight gain, slowed thinking, and even neurologic symptoms that may be confused with MS symptoms. Referral to the resident's physician for assessment of thyroid function should be made if there is an unexplained worsening of symptoms.
- ***Arthritis and Fibromyalgia:*** The aches and pains of arthritis and fibromyalgia are often ascribed to MS, since about half of people with MS have nonspecific pain. Assessment of pain should consider fibromyalgia and arthritis.
- ***Insomnia:*** Sleep disturbances are common in the MS population and can exacerbate daytime fatigue. They may be related to nighttime muscle spasms, bladder disorders, pain, depression, or other factors. These disturbances in sleep must be assessed to determine specific contributing factors so that treatment may be designed appropriately.
- ***Obesity:*** Inactivity secondary to disability and depression may contribute to obesity. Treating this common health condition is challenging, as most assisted living residents with MS cannot participate in vigorous exercise. However, exercise as tolerated, diet, and medication should be considered, since obesity may contribute to a number of other serious health disorders. Given the deleterious effects of obesity on independence for many disabled individuals, assisted living residence staff should monitor residents' weights and provide a diet that meets nutritional needs and prevents serious weight gain.
- ***Immunizations:*** Recent studies indicate that influenza (flu) vaccination does not cause MS attacks or accelerate progression of the disease. Having MS should not preclude a resident from having a flu shot. The flu can be very serious in a person with MS who has compromised respiratory status, and the high fever accompanying flu may exacerbate MS symptoms. The decision should be made on an individual basis, in consultation with a physician, taking into consideration all health risks of both receiving and avoiding a flu vaccination.
- ***Hospice Care:*** It is quite appropriate to bring in hospice care for very sick residents with MS, as permitted by state regulation for assisted living residences. Hospice professionals are skilled in developing palliative care plans and helping the resident, staff, and family members deal with the care challenges and emotional responses associated with end-of-life. This can be particularly difficult for all concerned due to the younger age of most residents with MS.

Rehabilitation Issues

Rehabilitation is a multidisciplinary approach to maximizing independence and minimizing the impact of impairments on daily functioning. In some assisted living programs, comprehensive rehabilitation therapies (occupational, physical and speech therapies) are not part of the usual cluster of services offered to residents. Residents who require rehabilitation services are generally referred to therapists in the community.

Some assisted living programs do provide on-site group exercise and wellness programs and, in some states, direct care staff may be trained to provide routine, maintenance therapies such as stretching and range of motion.

MS symptoms such as spasticity, tremor, weakness, fatigue, incoordination, gait disturbances, and sensory deficits, even when mild, may all interfere with independence and safety. Many of these symptoms can be successfully addressed by rehabilitation therapies.

Rehabilitation is an important component of care for people with MS, regardless of their level of disability. A customized program of physical therapy, occupational therapy, and speech therapy can minimize or prevent complications and health problems related to inactivity, improve comfort and quality of life, and optimize functioning for persons with MS.

TIPS: Rehabilitation

1. Provide the opportunity for individual consultations with physiatrists, occupational therapists, physical therapists, speech therapists, neuropsychologists, psychiatrists, and other appropriate staff (e.g., orthopedists, assistive technology experts) either on-site or by referral to provide support in improving mobility, safety, and ADL independence. Residents with MS benefit from access to these rehabilitation professionals who can provide assessment and prescribe a home exercise program or suggest on-going therapy with a professional in the community.
2. If a home exercise program is prescribed, direct care staff at the assisted living residence should be trained in the appropriate supervision of the resident and/or in ways to safely assist the resident perform the home program.
3. Rehabilitation professionals can also be instrumental in helping people with MS adjust to disability and develop realistic life goals.
4. Provide on-site group exercise and health-promotion programs. This type of program provides the opportunity for socialization and peer support as well as therapeutic exercise (e.g., stretching, range of motion) and health promotion training (e.g., stress management, energy conservation, symptom management).
5. On-site leaders of group exercise programs, if they are not professionals, should receive training and supervision from a rehabilitation professional. The National MS Society can be a good source of information about these types of programs and may be able to offer training and/or referral to potential group leaders.
6. Leaders of exercise groups should take special notice of the stamina of participants with MS and consider building rest periods into their program.
7. With varying levels of movement ability, it might be beneficial, if feasible, to offer several levels of exercise groups.
8. If music is used for exercise groups, the younger generation should be represented in the music choice.
9. Offer referral for assessment of wheelchair and other equipment needs. Maximizing mobility may encourage increased socialization, access to the community, participation in facility-sponsored activities and an increased sense of control over one's schedule. Proper equipment can improve comfort, independence, and mobility, as well as safety.
10. Provide for quick and regular wheelchair maintenance and repair. Developing a good relationship with a wheelchair supplier/repair service off site or identifying an in-house staff member with mechanical/technical skills may address this need at a basic level. Provide direct care staff with training concerning the proper use and cleaning of the wheelchairs, how to charge power chairs and proper use of other adaptive equipment.

SECTION 5

Staffing and Training

Trust is an important component in all staff-resident relationships. All residents need to be approached with sincerity, concern, and respect, and it is only through open communication and dialogue that relationships of sensitivity and cooperation can be established. Due to the myriad of losses and diminished sense of control that residents with MS have had to endure, to be treated with dignity, to feel a sense of autonomy and choice, and to be encouraged to direct and participate in one's own care is particularly empowering and meaningful.

It is unlikely that direct care staff in assisted living residences will have extensive previous experience or knowledge of multiple sclerosis. Therefore it is essential that training be provided to help staff deliver a high standard of care that can meet the resident's needs and be responsive and sensitive to the particular issues and challenges that are part of living with MS.

TRAINING PROTOCOLS

The following content should be included in the education and training protocols for the direct care staff.

MS: The Disease

- The fundamentals of MS, including the disease process, manifestations, and management of the disease and its symptoms. The National MS Society is an excellent resource for training materials and trainers.
- The progressive course of MS is slow moving. Although staff will see increased disability occur over the years, there is very little chance that it will occur rapidly. However, staff will need to be prepared to be flexible about changing needs.

Psychosocial Issues

- Training to understand the psychosocial, emotional and family issues related to MS and how they can affect daily routine and relationships
- The role of depression in MS and how to be sensitive and appropriately responsive
- Recognition of the challenge for new residents who must accomplish daily routine tasks in a new environment

Mobility

- Proper use of assistive devices—walkers, canes, wheelchairs (manual and power)
- The specific safety risks that can occur with people with MS
- How to provide supervision, cueing and other safety measures
- Assistance with safe resident transfers including, sit to stand, stand to sit, transfers in/out of bed, on/off the toilet
- Recognition that residents with MS are often heavier and less frail than geriatric residents and that spasticity and spasms can make transfers more difficult

ADL Management

- Ability to properly assist a resident to perform bathing, dressing, toileting, showering, grooming tasks
- Attention to sensory deficits that may make the resident at risk for burns, scrapes, pressure sores; knowledge of performing a skin check
- Maintenance of adequate nutrition and hydration
- Offering as much resident choice and independence as possible regarding activities of daily living
- Focusing on age-related activities of daily living that are not frequently seen in elderly residents. These may include shaving and leg waxing, or applying daily makeup. Also, younger women may still be menstruating and will require assistance with management of their periods.

Monitoring of Health Status

- Symptoms such as fever or increased fatigue as warning signs in MS
- Identification of safety risks and needs that must be communicated to appropriate administrative staff promptly
- Recognizing when a home health referral may be needed to bring in extra supports during times of disease flare-up. This will allow the resident to remain in their familiar residential setting and receive the necessary support to maintain their safety

Cognitive Issues

- Addressing behavioral and cognitive problems. An understanding of the emotional responses that may accompany MS, as well as the potential for cognitive dysfunction, may help direct care staff be more sensitive to how these issues influence behavior and interpersonal relationships on a day-to-day basis. For example, a resident may be demanding to a direct care staff during ADL routines. There may be angry outbursts or inappropriate behavior. Understanding the emotional impact of the loss of control that accompanies severe MS and the possibility that the resident is compensating for such loss by controlling people around him/her may help the direct care staff be more tolerant of the behavior and identify solutions for better managing the relationship.

Community Resources

- Staff should not assume that, just because someone has been diagnosed, the individual and their family will know all about the disease process and available community resources. The local chapter of the National Multiple Sclerosis Society can be an excellent resource for information to residents and their families and provides a wide range of educational and supportive services that might be helpful to them.

Resources

ROLE OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

The National Multiple Sclerosis Society recognizes that these suggestions will not always be easy to institute and is committed to working in partnership with assisted living facilities to make the job easier. Your local chapter, which can be reached by dialing 1-800-FIGHT-MS, can be called upon for advice and assistance in many areas. Written materials on MS and its symptoms can be made available to both staff and residents. A chapter representative may be able to come to your facility and in-service your staff on MS in general and on specific symptom management when needed. Many local chapters have support groups and exercise programs that would be available to residents at no charge. Larger chapters may be able to assist with on-site programs for those facilities serving several people with MS. Such programs could include in-house support groups, exercise/wellness programs, and on-site educational, social, or family programs.

The Professional Resource Center: The Society also supports a national Professional Resource Center (PRC). This Center provides information and multidisciplinary expertise about the disease and its management to health care professionals and is an excellent source of information and consultation on clinical care and medical management of MS. The Center can be reached at 1-866-678-7328, or via e-mail at HealthProf_info@nmss.org.

ORGANIZATIONS

- The National Multiple Sclerosis Society—www.nationalmssociety.org. In addition to the professionally oriented activities described above, the Society also offers education, support, and assistance to people with MS and their families.

- International Organization of MS Nurses—www.iomsn.org
- Consortium of MS Centers—www.mscare.org
- American Assisted Living Nurses Association—www.alnursing.org
- American Association of Homes and Services for the Aging—www.aahsa.org
- AARP—www.aarp.org
- American Seniors Housing Association—www.seniorshousing.org
- Assisted Living Federation of America—www.alfa.org
- Consumer Consortium on Assisted Living—www.ccal.org
- The National Academy for State Health Policy—www.nashp.org
- The National Center for Assisted Living—www.ncal.org

VIDEO RESOURCES

- "A Covenant to Achieve Healthy, Affordable and Ethical Aging Services"—www.aahsa.org
- "Assisted Living: A New Approach to Care"—www.alfa.org
- "Body Mechanics: Ergonomic Training for Long Term Care Staff"—www.ahca.org
- "But You Look So Well"—The emotional, social, and concrete impact of MS on the lives of four individuals and their families. Participants share their stories of living and striving to cope on a daily basis with this difficult illness. Also, a prominent neurologist provides information on the disorder and shares his views on how people can learn to live their lives with MS.—www.aquariusproductions.com
- "Choosing Assisted Living: What You Need to Know"—www.ccal.org
- "Communicating Matters"—How to communicate better with people whose communication skills have been compromised. Video and accompanying discussion guide.—www.healthpropress.com
- "My Body Is Not Who I Am"—Introduces viewers to people who openly discuss the struggles and triumphs they have experienced living in a body that is physically disabled. They talk honestly about the social stigma of their disability and the problems they face in terms of mobility, health care, and family relationships, as well as the challenges of emotional and sexual intimacy.—www.acquariusproductions.com
- "Not on the Sidelines: Living and Playing with a Disability"—www.fanlight.com
- "Resisting Care . . . Putting Yourself in Their Shoes"—www.fanlight.com
- Video Guide to (Dis) Ability Awareness"—www.fanlight.com

ASSISTED LIVING PUBLICATIONS

- "A Guide to Research Information for the Long-Term Care Industries: Assisted Living Communities and Nursing Homes," 1999, ALFA.—www.alfa.org
- "A National Study of Assisted Living for the Frail Elderly: Report on In-Depth Interviews with Developers" Barbara B. Manard and Rosemary Cameron, The Lewin Group, Inc., 1997, for Department of Health and Human Services.—http://aspe.hhs.gov/daltcp/reports/indepth.htm
- "Assisted Living in Your Community"—A process guide for local officials and community groups developing assisted living for seniors and persons with disabilities.—www.ccal.org
- "Assisted Living State Regulatory Review 2004," NCAL—Reviews state requirements for staffing requirements.—www.ncal.org
- "Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations"—The Assisted Living Workgroup, 2003.—www.alworkgroup.org
- "Beyond 50 2003: A Report to the Nation on Independent Living and Disability"—Includes results of the first ever national survey of Americans age 50+ with disabilities. The report documents the gap between what they say they need and what is available. Request from the AARP.—www.aarp.org
- "Overview of the Assisted Living Industry 2000 & 2001 Supplement," ALFA—Two reports on the status and future trends in assisted living with information on independent living and Alzheimer's statistics.—www.alfa.org
- "Senior Housing State Regulatory Handbook, 2003", ASHA—Reviews state licensure and regulatory requirements for assisted living residences and CCRCs. Provides state agency contact information.—www.seniorshousing.org
- "State Assisted Living Policy 2002," National Academy for State Health Policy—Covers administrators' requirements and state regulations regarding minimums for awake staff and for units serving residents with dementia.—www.nashp.org
- "The Policy Book: AARP Public Policies 2003"—Includes information on long term care, assisted living, and services for people with disabilities.—www.aarp.org

STAFFING RESOURCES

- "Family Members' Views: What is Quality in Assisted Living Facilities Providing Care to People with Dementia?" Catherine Hawes, Angela Greene, Merry Wood, and Cynthia Woodsong—Discusses staff qualifications and adequate staffing levels important to family members of assisted living residents with dementia (Study for Alzheimer's Association, 1997).—www.aspe.hhs.gov/daltcp/reports-f.shtml#Hawes4
- "High Service or High Privacy Assisted Living Facilities, Their Residents and Staff: Results from a National Survey," Catherine Hawes, Charles Phillips, and Miriam Rose—Examines the adequacy of staffing levels in assisted living facilities. 2000.—http://aspe.os.dhhs.gov/daltcp/reports/hshp.htm
- "Quality Measurement in Assisted Living and Residential Care Facilities," Catherine Hawes, Principal Investigator—For information, contact hawes@srph.tamu.edu
- "Recruitment and Retention Strategies for Assisted Living Facilities," ALFA—Reports on "best practices" in the AL industry for recruitment and retention.—www.alfa.org/public/articles/Hrwhitepaper.pdf
- "Results of a Follow-Up Survey to States on Career Ladder and Other Initiatives to Address Aide Recruitment and Retention in LTC Settings," North Carolina Division of Facility Services—Reports on a survey of states to find out what states are doing to address staff recruitment and retention in LTC settings.—http://facility-services.state.nc.us/careerna.pdf
- "Activities of Daily Living: Nine Ways Not to Get Hurt" (Assisted Living Version)—www.ahca.org
- "Managing Activities and Recreation Services"—Certification course and manual.—www.alfa.org
- "Managing Difficult Behavioral Symptoms"—Instructor and staff manuals.—www.ahca.org
- "Negotiated Risk Agreements in Assisted Living Communities", 2000—www.alfa.org
- Safety Training—Course materials include instructor guides, staff manuals, and video.—www.alfa.org
- "Quality of Life"—Instructor and staff manuals.—www.aahca.org
- "Staffing for Success in Assisted Living"—www.ahca.org
- "Staff Training in Assisted-Living Residences" (STAR), Program at University of Washington, funded by a 5-year Pioneer Grant from the Alzheimer's Association.—For information, contact 206-221-3857
- "Supervising Front-Line Staff"—Certification course and manual.—www.alfa.org
- "Workforce Excellence: Effective Tools to Recruit and Retain"—www.aahsa.org

ACCESSIBILITY, ENVIRONMENTAL DESIGN, AND ASSISTIVE TECHNOLOGY RESOURCES

- ADA Accessibility Guidelines for Buildings and Facilities (ADAAG) as amended through September 2002.—www.access-board.gov
- "Aging, Autonomy, and Architecture: Advances in Assisted Living"—www.aahsa.org
- The American Institute of Architects (AIA) has a workgroup updating assisted living guidelines for their "Guidelines for Design and Construction of Hospital and Health Care Facilities", 2005 edition.—www.aia.org
- "Design for Assisted Living—Guidelines for Housing the Physically and Mentally Frail" by Victor Regnier—Qualities and characteristics of best environmental designs.—www.aahsa.org
- "Going to the Source for Accessibility Assessment" by Phyllis Cangemi, Wayne Williams, and Paul Gaskell on how to make outdoors/nature accessible—http://www.wholeaccess.org/accessibility.html
- PVA's Architecture program promotes accessible design through technical assistance services, standards development, design guides, and building-code initiatives. These efforts increase housing and employment.—www.pva.org
- "Quantitative Assessment of Tremor in Multiple Sclerosis Patients: A New Technique" by M. L. Aisen, M.D. & N. G. LaRocca, Ph.D. *Assistive Technology Journal,* Vol. 1, on-line at—www.resna.org
- Uniform Federal Accessibility Standards (UFAS)—www.access-board.gov

WEBSITES

- Abledata—Sponsored by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.—www.abledata.com
- Access Board—An independent Federal agency devoted to accessibility for people with disabilities.—www.access-board.gov
- Adaptive Technology Resource Centre—www.utoronto.ca/atrc
- Alliance for Technology Access—A national network of technology resource centers, organizations, and companies facilitating empowerment of people with disabilities through technology.—www.ataccess.org
- Assistivetech.net—www.assistivetech.net
- Association of Tech Act Projects—www.ataporg.org
- Center for Assistive Technology, SUNY, Buffalo—www.cat.buffalo.edu

- Center for Assistive Technology & Environmental Access, Georgia Tech—www.catea.org
- Center for Computer Assistance to the Disabled—CCAD is a non-profit organization whose mission is enhancing the quality of life and employment options for persons with disabilities.—www.c-cad.org
- Center for Universal Design, North Carolina State University—Resource center site listing many sites.—www.design.ncsu.edu/cud/
- DisabilityInfo.gov—Central governmental website for information related to accessibility and assistive technology resources and programs.—www.disabilityinfo.gov
- Infinitec—A joint effort of the United Cerebral Palsy Association of Greater Chicago and United Cerebral Palsy Associations, Inc., Washington, D.C.—www.infinitec.org
- It's Never 2 Late—www.IN2L.com
- Lemelson Assistive Technology Development Center—http://lemelson.hampshire.edu/
- National Center on Accessibility—www.ncaonline.org
- National Multiple Sclerosis Society—www.nationalmssociety.org
- New Horizons Un-Limited—www.new-horizons.org
- Online MS Management—www.MSwatch.com
- Rehabilitation Engineering Society of North America (RESNA)—www.resna.org
- USA Tech Guide—www.usatechguide.org

ASSISTED LIVING PROGRAMS FOR RESIDENTS WITH MS AND OTHER DISABILITIES

- The Manor at Knott Avenue—The Orange County Chapter of the National MS Society works collaboratively with The Manor to foster quality programs and services for their MS residents. Contact 714-821-2130. Administrator Jane McTeir
- Harmony Assisted Living—An assisted living residence specializing in the younger disabled (under 55 years of age). The Rocky Mountain MS Center provides supportive services to Harmony residents, including companions, adaptive equipment, and transportation services. Contact 303-433-0906. Administrator Paula Padilla
- Individual Care of Texas, Inc. and Highland Assisted Living, L.L.C.—Assisted living for residents with physical or mental disabilities. www.individualcareoftx.com/index.htm

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