



NATIONAL
MULTIPLE SCLEROSIS
SOCIETY



Nursing Home Care of Individuals with Multiple Sclerosis: Guidelines & Recommendations for Quality Care



**National Multiple Sclerosis Society
Long-Term Care Committee**

Professional Resource Center

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The National Multiple Sclerosis Society . . . One thing people with MS can count on.



CONTENTS

Contributors/Reviewers	iii
Preface	v
Resident Profile	vii
Section 1: Overview of Multiple Sclerosis	1
Section 2: Guidelines and Standards for Care	5
Clinical and Nursing Issues	5
MS Symptom Management	5
Complications of MS	17
Primary Health Care Needs	20
Psychosocial Issues	25
Daily Care Issues	27
Rehabilitation Issues	30
Availability of Rehabilitation Services	30
Wheelchairs, Equipment, Physical Environment, and Assistive Technology	31
Neuropsychological Issues	34
Section 3: The Nursing Home Admission Process	37
Section 4: Training Materials and Resources	39
The National Multiple Sclerosis Society	39
Programs Offered by the NMSS	40
Collaboration with Local NMSS Chapters	41
Professional Resource Center	42
Nursing Home Task Force	42

Paralyzed Veterans of America (PVA)	42
MS Clinical Practice Guidelines	42
MS Training Materials	43
Models of Specialized Nursing Home Care	43
Appendix A: Medications Commonly Used in MS	45
Appendix B: Recommended Resources	49
General Readings	49
Demos Medical Publishing	49
Additional Recommendations	50
Information from the National Multiple Sclerosis Society	51
Books for Healthcare Professionals	51
Booklets for Lay Audiences	51
Materials Available in Spanish	52
Other MS Society Publications	52
Web Sites	52
Organizations	54
Index	59



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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 the care of people with MS in the nursing home setting, but is not meant to substitute for, or to supersede, individualized physician treatment and advice.



PREFACE

This document was developed by the National Multiple Sclerosis Society (NMSS) to provide guidance to clinicians and administrators of long term care facilities that are seeking to develop more effective care plans to 1) manage the unique set of clinical conditions of their residents with MS, and 2) maximize the quality of life for these residents.

Multiple sclerosis is a complex, chronic disorder of the central nervous system that often generates needs for a range of long-term care services, including rehabilitation services, home care, adult day care, assisted living, and nursing home care. While only about 5–10% of the MS population require chronic nursing home care, these individuals need targeted, specialized care that many nursing homes do not have experience providing. When traditional geriatric care is not modified for this population, the long-term care experience becomes more difficult than it need be for both the staff and the residents. As compared to the frail elderly nursing home resident, residents with MS in nursing homes tend to:

- ⊙ Be younger
- ⊙ Be more mentally alert
- ⊙ Be more physically dependent
- ⊙ Present with more symptoms of depression and
- ⊙ Have a longer length of stay¹

As a result, nursing home staff requires additional training and resources to best meet the needs of this unique population.

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 brought together an expert panel of NMSS home office and chapter staff, and MS specialists in the fields of mental health, social service, and long term care, to identify the key components of a quality nursing home program for residents with MS. This task force contributed their knowledge and clinical expertise to the preparation of this document through a series of meetings, research on best practices and preparation of several draft documents.

¹Buchanan RJ, Wang SJ, Ju H. Analyses of the minimum data set: comparisons of nursing home residents with multiple sclerosis to other nursing home residents. *Multiple Sclerosis* (2002) 8: 512–522.

This document is thus designed to be a practical resource for nursing staff, rehabilitation professionals, social workers, mental health professionals, and others involved in the direct care of nursing home residents with MS. It is organized as follows:

- ⊙ First, we provide some background on the disease itself, to provide the context for the delivery of care.
- ⊙ Next, we provide guidelines and standards of care in the areas of clinical/nursing issues, psychosocial functioning, daily care, rehabilitation, and neuropsychology.
- ⊙ Third, we discuss some aspects of the nursing home placement and admission process.
- ⊙ Fourth, we offer resources and materials for additional information and training of nursing home staff and other professionals involved in providing MS care.
- ⊙ Finally, we offer two appendices: Medications Commonly Used in MS, and Recommended Resources.



RESIDENT PROFILE

Julie is not a factual person, but a composite of several residents at a specialized long-term care facility for residents with MS.

Julie is a 48 year old, single, white female who was admitted four years ago with a diagnosis of MS. She is a college graduate with an advanced degree in education and worked with learning disabled children prior to her admission. She had lived alone and taught in a large school system. Her family consisted of her elderly parents, one sister and one brother who were both married with young children. Her brother lived out of state but her parents and sister lived nearby. Julie had always been very independent and took great satisfaction in being able to run her own life.

In her mid-thirties, she had an episode of blurred and diminished vision and had gone to her ophthalmologist to find out what was happening. He discovered optic neuritis and suggested she see a neurologist. She was subsequently diagnosed with MS. The diagnosis came as a shock, as she was quite healthy. She continued teaching but soon other symptoms appeared. She was embarrassed about her unsteady gait and worried that people might think she had been drinking. She began to have trouble remembering appointments and processing information. Her reasoning and problem solving were also diminished. Her disease progressed rapidly. She experienced trouble walking and progressed from using a cane to a wheelchair. These mobility issues and the cognitive decline ultimately caused her to resign her teaching position. She began receiving visiting nurse services (a home health aide) several days each week. By age 40, she was experiencing frequent falls at home, requiring her to call the fire department to assist her. She had trouble remembering to take her medications and needed more and more help at home. Her parents were unable to provide enough assistance, as they were elderly, with health problems of their own.

She was admitted to the nursing home angry and frightened, when it seemed she could no longer manage at home. The first several months were difficult as she tried to struggle with the loss of her independent life. She found that the constant company of others (including a roommate who played the TV too loud) and lack of privacy were difficult to adjust to. She resented having to share her aide with other residents and having to follow a schedule that was not always her choice. She hated the Hoyer lift and all the other assaults to her independent spirit.

After a year, Julie was unable to mobilize her own manual wheelchair. The facility obtained a power chair for her and she loved the new freedom. She was able to go

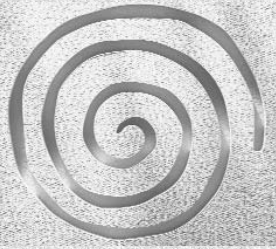
outdoors and find a private spot on her own and was able to explore the neighborhood, and visit the local library and shops with other residents.

Julie's vision became worse and her speech difficult to understand. She also had problems operating her power chair. The chair was modified with head controls, but she still had difficulty controlling it, at one point running into another resident and a staff person (who needed to go to the emergency room for care). While everyone wanted Julie to be able to maintain her independence, they were also very concerned for her safety and that of others in the facility.

The next problem Julie encountered was difficulty feeding herself. She hated having to be fed by an aide. She also had difficulty swallowing and began to choke on her food, but refused a modified (pureed) diet. She felt this was as demeaning as eating baby food. A speech therapist evaluated her swallowing ability and recommended a feeding tube. Julie had clearly specified her wishes against this in her Advanced Directive.

* * *

Julie's story highlights the many challenges faced by the nursing home resident with MS as well as the staff who are trying to best meet her needs. She is a younger than expected nursing home resident who requires total care from nursing staff and at the same time desires and insists on being independent and self-directed. These characteristics unite to place challenging demands on the nursing home staff and on Julie to collaboratively develop a care plan that provides for her safety and health while promoting her independence.



Overview of Multiple Sclerosis²

Below is a general description of multiple sclerosis that accurately describes the overall MS population. Nursing home residents with MS on the whole, however, differ from most individuals with MS living in the community. Most nursing home residents have the most severe form of the disease, and such symptoms as severe cognitive dysfunction and complete paralysis are much more prevalent in the nursing home population. Furthermore, the small percentage of people with MS who may have a fatal course or significantly shortened life expectancy are concentrated in nursing home settings.

Multiple sclerosis (MS) is a chronic, frequently progressive, neuroimmunologic disease that attacks the myelin sheath surrounding the axons in the central nervous system (CNS—brain, spinal cord, and optic nerves). Demyelination occurs, often at multiple sites throughout the CNS. Irreversible damage to the axons themselves can also occur, even in the earliest stages of the disease. It is hypothesized that an external “trigger” such as a virus or bacterium may precipitate an autoimmune response in genetically susceptible individuals. The inflammatory, demyelinating process can result in a wide variety of symptoms, including gait disturbances, sensory complaints (numbness, paresthesias, burning, feelings of constriction or pain), visual problems, fatigue, incoordination, bladder, bowel, and sexual dysfunction, and partial or complete paralysis in severe cases. While cognitive impairment occurs in approximately 50% of people with MS, only 10% experience serious intellectual deterioration.

The cause and cure of MS are unknown, although symptomatic management is possible and certain immunoregulatory agents reduce the relapse rate and may also slow disease progression.

²Excerpted from *Basic MS Facts* by Nancy Holland, EdD, Clinical Bulletin, Professional Resource Center, NMSS, revised 2002.

It is important to note that MS is not contagious, is not usually fatal, or hereditary, although a genetic predisposition is probable and being studied. Onset of symptoms for the majority of people with MS occurs between the ages of 20 and 50. The composite picture of a person with MS is: Caucasian (whites are diagnosed more often than other racial groups), 30 years of age, female (females are affected more than twice as often as males) and living in one of the temperate areas of the world.

In general, the nearer to the equator a person lives, the less risk he/she has of acquiring MS. In the U.S., the estimated prevalence rate is 100–150/100,000, above the 37th parallel. Below the 37th parallel the rate is 57–78/100,000. Overall, perhaps 400,000 people in the U.S. have MS.

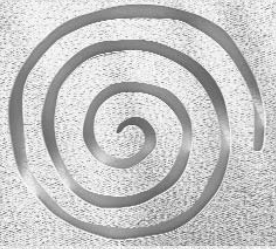
There is no single definitive diagnostic test for MS, although certain laboratory tests are commonly used to support neurologic findings that suggest MS. Diagnosis is primarily established by patient history and neurologic examination. Magnetic resonance imaging (MRI) and electrodiagnostic procedures such as evoked potential measurement are often helpful to confirm a suspected MS diagnosis. Lumbar puncture, often needed to firmly establish the diagnosis of MS, is positive when oligoclonal bands or other evidence of immunoglobulin synthesis are present in the cerebrospinal fluid (CSF).

The clinical course of MS usually falls within one of the following categories, with the potential for progression from one pattern to a more serious one:

- ⊙ **Relapsing-Remitting MS:** Persons classified as having relapsing-remitting MS experience clearly defined relapses—episodes of acute worsening of neurologic function—followed by periods of remission without disease progression. In some cases, people experience a residual deficit.
- ⊙ **Secondary Progressive MS:** People with secondary progressive MS experience a relapsing-remitting disease course at onset, followed by progression with or without occasional relapses, minor remissions, and plateaus. Although the disease usually begins in the relapsing-remitting category, most individuals eventually convert to the progressive category.
- ⊙ **Progressive-Relapsing MS:** Persons with progressive-relapsing MS experience progressive disease from onset, with clear, acute relapses that may or may not resolve with full recovery. Unlike relapsing-remitting MS, the periods between relapses are characterized by continuing disease progression.
- ⊙ **Primary Progressive MS:** People with primary progressive MS experience a nearly continuous worsening of disease that, by definition, is not interrupted by distinct relapses. Some of these individuals do have occasional plateaus and temporary minor improvements. Health professionals tend to have greater exposure to individuals with the more serious forms of the disease. Therefore, it is important to note that the majority of individuals with MS do not become severely disabled.

Management of MS involves the following:

- ◎ **Symptomatic Management:** Improve function, relieve discomfort, and prevent complications and secondary disability through medical and rehabilitation therapies.
- ◎ **Quality of Life Interventions:** Address psychosocial and other issues regarding coping and adaptation.
- ◎ **Relapse Management:** Treat acute relapses (flare-ups, attacks, exacerbations) in order to shorten the duration and reduce the severity. Most physicians prescribe IV steroids to treat those relapses that are severe.
- ◎ **Disease Modification:** Reduce number of relapses, rate of progression and development of new lesions; currently approved are Betaseron[®], Avonex[®], Copaxone[®], Rebif[®], and Novantrone[®].



Guidelines and Standards for Care

These guidelines, while specific to multiple sclerosis for our purpose here, may well apply to other nursing home residents. Many of the recommendations regarding psychosocial issues and quality of life are relevant to all adults. Few studies at this time are specific to the long term care of individuals with advanced stages of MS. The following guidelines and standards are based upon scientific and clinical information currently available and the practical experience of the long-term care facilities' staff that specialize in this type of care.

CLINICAL AND NURSING ISSUES³

While some of the symptoms of MS are seen in other disorders and may be familiar to nursing home staff, the severity, clustering, and nature of these symptoms present a unique challenge to nursing and rehabilitation management. It is crucial that nursing home staff be aware of the unique ways these symptoms present in persons with MS, the impact on their day-to-day lives, and potential treatments and strategies for management of care.

MS Symptom Management

Clinicians should be aware of the following symptoms as they develop a daily care plan for residents with MS:

³Some material above adapted from Halper J, Murray JT: Primary care needs of MS patients. In van den Noort S, Holland N (eds.): *Multiple Sclerosis in Clinical Practice*. New York: Demos Medical Publishing, 1999; and from Halper J, Holland N: *Comprehensive Nursing Care in Multiple Sclerosis* (2nd ed.). New York: with permission of Demos Medical Publishing, 2002.

Spasticity

Management of spasticity or muscle hypertonia is a challenge because of concurrent symptoms such as weakness and fatigue.

Management consists of stretching programs and pharmacologic agents such as baclofen, diazepam, dantrolene sodium, and tizanidine. Some patients with severe spasticity have benefited from intrathecal baclofen delivered by an implantable pump. Botulinum toxin injected directly into the muscle has also been beneficial to some patients. The use of phenol blocks and surgical techniques, while beneficial to some, are used less frequently since the advent of the baclofen pump. If spasticity is not managed, complications such as skin breakdown, contractures, and pain can occur.

TIPS: Spasticity

1. Health care workers need to be reminded that muscle spasms are involuntary. Telling the resident to “relax” will likely make things worse. It is best to stop whatever you are doing with the resident, if possible, and wait until the spasm passes before proceeding.
2. Avoid quick, sudden movement of the resident’s limbs that can set off spasms. Instead, tell the resident what you plan to do and rest your hands firmly on the limb before moving it. Move slowly and smoothly.
3. Stretching is different from the passive range of motion that is taught to nursing assistants in their basic training. It is slower and positions are held longer. It is advisable to train a few “restorative aides” to provide these stretching exercises to residents. A typical maintenance schedule is 20 minutes 3 times a week. While these exercises can be done in bed, it is preferable to perform stretching on a physical therapy mat for maximum stretch and for minimal risk of muscle strain to the aides.
4. Spasticity increases the risk of injury to the nursing assistants during pivot transfers. These residents should always be transferred by an electric lift with 2 persons in attendance. Electric lifts are preferable to mechanical lifts because the lifting motion is smoother and less likely to stimulate a spasm.
5. Residents with spasticity should be encouraged to always wear seat belts when out of bed in a shower chair, wheelchair, or recliner. A sudden spasm can cause them to slide out of the chair or even topple a commode chair. The seatbelt serves as a positioning device to stabilize their trunk during spasms—not as a restraint.

Tremor

The most common tremor in MS is a slow gross intention tremor that occurs with purposeful movement of the arm or leg. This type of tremor is often exaggerated with stress.

Some drugs, including hydroxyzine, clonazepam, propranolol, primidone, and isoniazide may help in addition to physical techniques, e.g., weighting, immobilization, and patterning. Tremors are very challenging to control. Speech therapy may help control tremors of the lips, tongue, and jaw.

TIP: Tremor

1. Tremor and spasticity can significantly impair a resident's ability to drive their power wheelchairs. Providing good arm support so that the resident's arm is at rest while driving, and joystick controls that require only a "light touch" may improve their driving ability. Seek out wheelchair seating specialists at rehabilitation centers and/or wheelchair companies for consultation.

Balance

Balance problems often result in an unsteady gait or trunk instability.

Therapeutic exercises with a Swiss Ball and other techniques that challenge the patient's balance may be helpful in stimulating balance centers and improving balance but occupation and physical therapy measures for appropriate support while sitting may be necessary. Attention to sitting balance is an important safety concern.

TIPS: Balance

1. A chair alarm that is clipped to the resident's clothing can be helpful as a reminder to residents with poor balance to "sit back." The alarm goes off when they are leaning too far forward and can call staff if the resident has lost their balance and is slumped over the side of the chair.
2. 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.
3. Use lift slings made of mesh and without bulky seams and leave them under the resident when they are sitting in the wheelchair. This will allow the nursing assistants to easily re-attach the lift and reposition residents who have slumped over in their chairs.

Weakness

Weakness may result from both disuse and from interrupted neurotransmission.

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

Fatigue

People with MS may experience normal fatigue, fatigue of depression, the fatigue of disease, and the fatigue of neuro-muscular overuse.

MS fatigue, an overwhelming lassitude, may be treated with amantadine, fluoxetine, or methylphenidate. A newer approach includes use of modafinil, a drug approved for the treatment of narcolepsy. Occupational therapists can advise on energy saving techniques. Overheating should be avoided.

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.
2. Nursing home routines often trigger fatigue in MS residents. Try to schedule therapy and activities and meals with rest periods in between. It may not require that the resident go back to bed but simply have some "quiet" time with their wheelchair in tilt position to conserve energy.
3. Guided meditation is a useful activity to manage fatigue.
4. Provide most nutrition through the morning and noontime meals. Most residents with MS are too tired in the evening to eat hearty meals.
5. Always consider poor hydration as one cause of fatigue particularly in residents with difficulty swallowing liquids.

Vision

Optic neuritis, causing pain and acute vision loss is common in MS as is double vision and nystagmus. Cataracts may develop at a younger age in persons with MS because corticosteroids 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 a neuroophthalmologist or low vision center.

TIPS: Vision

1. Most residents with MS require large screen TVs set on tables that can be wheeled close to their bedside.
2. Many 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 nursing home.
3. The easiest written material for residents with MS to read 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 wheelchairs with fewer collisions.

Paresthesia

Numbness and tingling are common in MS. Some residents with MS may experience sensitivity to touch or experience abnormal sensations in response to touch. Many residents with MS experience an electric shock sensation upon neck flexion called L'Hermitte's sign.

Sensory disturbances may present a safety concern in bathing and feeding (exposure to hot water, beverages, and food), smoking and wheelchair driving. Also, numbness may delay or prevent an individual from reporting that they have been incontinent.

TIPS: Paresthesia

1. Some residents with MS may experience a burning or stinging sensation on the soles of their feet that may last days to weeks before spontaneously ceasing. Gabapentin (Neurontin) may help but generally, comfort measures work best. The resident may prefer to not wear shoes or socks and to use a foot cradle while in bed. Light foot massage with topical anesthetics may provide temporary relief, as do ice packs at times. Reassure the resident that it will pass and try to distract them with socialization rather than allowing them to stay in bed.
2. Frequent skin checks during AM and PM care is essential since these residents seldom report collisions, scrapes and cuts because they either did not feel it, could not see it or forgot.

Bowel Dysfunction

People with MS may experience constipation as a result of inadequate fluid or bulk in the diet, decreased physical activity, medications, and from MS involvement that may slow the bowel or weaken abdominal muscles.

Interventions include increasing fluid and fiber intake, a routinized 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. These residents often have decreased sensation, so it is very important that there are two staff in attendance when administering an enema: one to hold resident in proper position while the other administers the enema. This provides the best visibility and access thereby diminishing the risk of injury to the rectum. Check the peri-anal area frequently for any signs of irritation. And double check the temperature of the enema since the resident may not be able to tell you that it is too hot.

Diarrhea may occur secondary to fecal impaction, overuse of laxatives, or medications. An additional complication from diarrhea may be skin irritation and breakdown. Uninhibited bowel elimination may also result from diminished sphincter control or hyperreflexive bowel. The dietician is essential in planning a diet that will provide sufficient bulk and fits the resident's diet modifications. S/he will also assist in identifying foods that may over stimulate a hyperactive bowel. A structured, daily plan for bowel management can lead to more predictable bowel habits.

TIPS: Bowel Dysfunction

1. By the time a person with MS comes to a nursing home to live, s/he is very familiar with constipation and most will have a "system" that they will want rigidly followed. These schedules may not fit the routines of a long-term care facility but abrupt changes will lead to substantial conflict with the resident and may also lead to constipation and impaction. Make modifications, slowly and incrementally and through negotiation with the resident.
2. Many persons with MS have decreased sensation and can sit on a bedpan or commode for long periods without discomfort. Some even forget that they are on a bedpan despite being alert and oriented. Do not rely on these residents to press their call light when they are ready to come off the bedpan or commode. Watch the time and check them frequently.

Bladder Dysfunction

Bladder dysfunction is very common in MS and may pose a serious threat to health.

Proper management is necessary to prevent urinary tract infections and dangerous urinary retention that may damage the detrusor (the primary bladder muscle).

Dysfunction may occur in the detrusor, external sphincter, or coordination of their functions. The detrusor can be hyperactive, signaling the urge to void at very low urinary volume, or hypoactive, allowing a dangerously large amount of urine to accumulate before signals to void are initiated. The external sphincter may contract during attempted urination, inhibiting urinary flow. Relaxation of the external sphincter is crucial, since even strong detrusor contractions will not empty the bladder if a tight sphincter blocks the exit. Anticholinergic medications, e.g., oxybutin (Ditropan XL), tolteradine (Detrol) as well as other medications that relax the external sphincter and facilitate urine flow may be helpful. The major side effects of these medications are dry mouth and constipation, which will, in turn, need to be

managed. Intermittent or indwelling catheterization are common interventions, depending on the type of dysfunction.

It is important to periodically reassess bladder status—particularly for post-void residual volume in non-catheterized persons. Only residents with symptoms (dysuria, fever) should be tested for UTI, as asymptomatic bacteriuria is extremely common in people with indwelling catheters. Treatment of asymptomatic bacteriuria has not been shown to improve outcomes. While there is ample evidence that persons with indwelling catheters suffer more urinary tract infections, constant dribbling of urine and/or urgency is so discouraging to persons with MS that they may start to withdraw from social situations—particularly outings of any kind. The quality of life benefits may outweigh the infection risk for some individuals. Should an indwelling catheter be necessary, a suprapubic tube should at least be considered. There is some evidence that there are fewer infections with suprapubic tubes. Many of the women with MS in nursing homes are still menstruating and are incontinent of bowel which compounds the problem of infection with indwelling catheters.

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

TIPS: Bladder Dysfunction

1. Cranberry extract in gel cap form is preferable to cranberry juice for prevention of recurrent urinary tract infection. The gel-caps can be opened and easily added to applesauce or pudding for residents with dysphagia or to flush through a gastrostomy tube. 400–500 mg BID is the usual dose.
2. Coffee can be very irritating to the bladder. Residents who suffer from urgency and/or bladder spasms should avoid caffeine and caffeinated beverages, but may enjoy decaffeinated coffee and soft drinks.
3. To keep urine diluted in residents with catheters, try attaching a large insulated cup with lid and corrugated straw—such as those from convenience stores and coffee outlets—to the back of the wheelchair or on the lap tray. If the straw is within reach of the resident’s mouth, s/he can sip liquids continuously all day.
4. Residents without catheters on toileting schedules should NOT sip fluids all day. They should drink most of their fluids with their meals and be toileted 60–90 minutes later.
5. Residents who are out of bed for long periods should wear high quality briefs—WITHOUT liners—that wick large amounts of urine away from their skin. The pennies spent on briefs that are more expensive will be saved many times over in skin care treatments.
6. There are many types of leg bags and even a “belly bag” which can be worn by residents with indwelling catheters when they are out of bed. This really helps maintain their sense of dignity.

Dysphagia

Abnormal swallowing is common in MS.

Alternatives to “normal” feeding such as positioning of the head and chin, changing the consistency of food and planning rest periods prior to feeding may help prevent choking and aid in adequate nutrition. Swallowing studies (barium swallow) are available as an outpatient procedure at most hospitals. They are best done in conjunction with the speech therapy service at the hospital to determine the exact nature of the resident’s swallowing problems. Do they tolerate thick liquids but not thin? Do they have a delayed swallow reflex? Do they pocket food in their cheeks? The swallow mechanism is complex and incorrectly modified diets may exacerbate the problem. Some residents with MS cannot swallow sufficient fluids in a 24-hour period to maintain hydration. With poor hydration, they become weaker and more fatigued. This in turn leads to even less intake. In other situations, the resident must eat such small bites of food that it would take nearly an hour for every meal to ingest sufficient nutrition. If the resident tires after 30 minutes, their risk of choking increases as the meal continues. If the meal is stopped, malnutrition may occur. A surgically placed feeding tube may be appropriate to maintain fluid intake while taking solid foods orally or to supplement inadequate caloric intake. While feeding tubes are controversial—particularly when viewed as prolonging suffering—many MS residents with feeding tubes enjoy renewed energy for activities and enjoyment of life. Feeding tubes can also be temporary for some residents with MS who experience increased fatigue and difficulty swallowing while recovering from an infection, surgical procedure, or an exacerbation of their disease.

TIPS: Dysphagia

1. Thickened iced tea and coffee resemble a coffee milkshake in texture and taste.
2. Always add the thickener just before serving the liquid. It is 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. Whenever possible, have nursing assistants who are very patient feed residents with swallowing disorders. Staff who have a hard time “slowing down” themselves will grow impatient with the time it takes to feed such a resident. Their tension will transfer to the resident and increase the likelihood of a choking episode.
5. If there is a microwave handy, reheat food after 20 minutes to make it more palatable.
6. Teach your staff how to perform the Heimlich maneuver on a person confined to a wheelchair.

Cognitive Changes

Memory, information processing, attention, concentration and judgment may be impaired in residents with MS. However, intelligence and language are usually intact.

Individuals with MS who require nursing home care usually have some cognitive impairment. Often it is the loss of judgment, information processing, and short-term memory that precipitates their admission because they are no longer safe to be alone at home for any period. It is the most significant challenge for the nursing staff in the long-term care facility when compared to other types of residents. In general, these residents are younger, well educated and their intellect is intact. They are alert and oriented and converse with the staff as peers. It is extremely disturbing to the nursing staff when the resident suddenly and

impulsively accuses them of not providing the care they needed because the resident has no memory of it. These residents can be very convincing to nursing home ombudsmen, administrators, and family members because they truly believe it did not happen. Staff feels betrayed and “abused” because the resident does not appear confused or demented. Other residents are “forever” on the call light because they either forgot that the aide just left the room or they are unable to organize their thoughts to ask for more than one thing at a time. They become labeled as “demanding” residents. A neuropsychology consult can be invaluable in order to define the cognitive issue(s) and work with staff and the resident to compensate for it. At a minimum, staff should be educated about these types of cognitive problems. More significantly impaired residents may gradually lose their ability to communicate at all with staff much as severely demented elderly residents do. Their intellect, however, may still be intact. Sensory stimulation groups, music therapy, relaxation therapy and prayer groups are appropriate activities for such residents when available. Sitting in a chair alone in his/her room, staring at a TV, is not appropriate unless it has always been their favorite program. As residents age, many will develop dementia requiring the more typical geriatric interventions. Wandering is seldom an issue due to the advanced physical impairments.

Epilepsy

Seizure disorders occur in about 5% of patients with MS.

Such residents usually respond to the usual anti-convulsants.

Hypophonia

As MS progresses, some people may develop difficulty in vocalizing.

To be properly heard, speech-augmenting devices should be prescribed by a trained speech therapist.

Respiratory Muscle Weakness

Weakness of the respiratory muscles due to MS predisposes patients to influenza and pneumonia.

Residents should be encouraged to receive both the influenza vaccine annually and the pneumovax (every 7–10 years). Residents with tracheostomies may need suctioning or respiratory treatments.

MS Exacerbation and Pseudo-exacerbation

Residents with symptoms of new weakness, confusion, decrease in functional abilities may be suffering from a flare-up of their MS.

In multiple sclerosis, common non-MS precipitants of decline should be excluded. These include pulmonary or bladder infection, medication reaction or other acute illness.

Complications of MS

Clinicians should be aware of the following potential complications as they develop a daily care plan for residents with MS:

Bladder Infection

Bladder infection is a common complication of neurogenic bladder.

Bladder infection may result in fever and “pseudo-exacerbation”. Infections are treated with antibiotics. Adequate fluids, cranberry juice or tablets, and good perineal hygiene are important in preventing infection. Prophylactic antibiotics are sometimes prescribed. Urinary retention should be ruled out by catheterization or use of bladder scanner.

Pressure Ulcers

Pressure ulcers in sedentary or bedridden patients are common.

Alteration in skin integrity and the development of pressure ulcers is a major concern of all long-term care facility staff. The non-ambulatory resident with MS should always be considered high risk and maintained on the facility’s high-risk protocols. In addition to the obvious risk due to decreased mobility and incontinence, there are those associated with spasticity (causing skin shear), impaired sensory awareness (residents often have no idea that they have just burned their finger, scraped a knee or need to be repositioned) and impaired cognition (may not report an injury). The Prevention and Treatment protocols published by the Agency for Health Care Policy and Research are equally effective with MS residents. The key is to use a simple and consistent approach that becomes second nature to the staff and residents.

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, provide fewer areas of pressure and allow the resident to stay up and out of bed for longer periods. Such wheelchairs may also be fitted with a tilt device that allows the resident (or staff) 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. (Check the resource section of this publication for contact numbers to assist you.) An appropriate mattress that has a shearless cover and pressure relief in heel and sacral areas is also critical for these residents to prevent skin breakdown.

(see TIPS for preventing pressure ulcers on next page)

TIPS: Pressure Ulcers

1. A weekly head to toe skin check by a nurse will reduce the number of Stage I areas that progress to ulcers that are more significant. In the MS resident with spasticity, it is important to check the back of the head carefully and the ear lobes, which can suffer shear injuries that might be overlooked. Coccyx may get shear damage from sliding in and out of bed.
2. Hospital or long-term care beds that automatically catch at the knees when the head of the bed is elevated are very effective in preventing shear on the sacrum, buttocks, and heels. These are often available as re-manufactured hospital beds at a considerable savings.
3. 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.
4. Not all MS residents require turning every 2 hours to prevent skin breakdown. But they all need a good night's sleep. If the resident's skin remains intact on the q 2-hour schedule throughout the night, try increasing the intervals to 2.5 hours for about 2 weeks—checking the skin q AM. You can continue this up to a maximum of 4-hour intervals to determine the resident's tolerance.
5. As with all long term care residents, when the resident gets sick, their risk factors intensify. So, increase the frequency of repositioning and skin checks.

Long-Term Use of Steroids

Long-term or repeated steroid use is not usually recommended as it may result in a number of complications.

Complications of long-term use may include: Cushingoid features, aseptic necrosis of the hip, cataracts and osteoporosis.

Pain

Pain in MS is often related to paresthesias, spasticity, tic doloreux, and postural problems.

Postural problems may cause significant back and neck pain that may be addressed with positioning strategies. Depending on the source and type of pain, various treatments may help, including antispasticity drugs, anti-convulsants, anti-depressants, and opioids. Intractable pain may require more invasive methods. 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. It is, however, more common for MS residents and their caretakers in long-term care to worry about “becoming addicted” to pain killers because they are younger and have a longer life expectancy than the other residents. In general, nursing staff in long-term care is also less comfortable than their acute care counterparts when it comes to using narcotics to manage pain. There are many excellent workshops, videos and manuals available to assist long term care facilities to address this challenging area.

TIPS: Pain

1. Nurses from local hospice agencies are a wonderful resource in terms of managing pain and identifying alternative modes of delivering pain medication for residents with dysphagia. They usually have a local pharmacy that prepares medication in suspension, patches, and “lollipop” form.
2. One type of pain that residents with MS may experience that is quite different from other residents of long-term care is a sensation of “burning” on the soles of their feet. It usually starts abruptly, lasts for days to weeks, and then ceases. Residents need reassurance during these spells and may find it more comfortable to go barefoot. Ice packs and anesthetic creams provide temporary relief for some residents. And distraction, i.e., involving them in socialization activities, is also useful.
3. Neuralgic facial pain is often mistaken as “tooth” pain. The resident may state that they feel like they have a tooth abscess. Lidocaine mouthwash may provide some relief on a temporary basis. Lidocaine patches directly on the cheek or jaw—while not attractive—also seems to relieve the pain.

Side Effects from Interferon Therapies

In patients beginning therapy with one of the interferon medications, there can be flu-like symptoms and spasticity can be aggravated and mistaken for a relapse.

Flu-like side effects are managed by reducing the dose, then titrating upward as symptoms subside. Also, NSAIDs (non-steroidal anti-inflammatory drugs) may control these flu-like symptoms. If side effects are intolerable, the patient might be switched to glatiramer acetate (Copaxone®). Copaxone is also used as the initial therapy by some patients.

TIP: Side Effects from Interferon Therapies

1. Call the manufacturer of the drug to provide your staff with their training materials. They are free and are usually well done.

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 and conditions may affect individuals with MS in a unique way, e.g., infections and fever. Residents with MS should adhere to the health-screening schedule recommended for all adults:

- ⊙ Periodic cholesterol testing in all adults starting at age 20. Patients already being treated for high cholesterol should be checked every two to six months.
- ⊙ 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 and glaucoma exam annually over age 65.
- ⊙ Hearing exam every 5 years over age 50.
- ⊙ DRE for prostate and colorectal cancers annually over age 40.
- ⊙ 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 and often not provided to nursing home residents. Potential difficulties in properly positioning someone with severe mobility for the test may lead to inattention to this and other important preventive health measures. Disability should not be an excuse for deferring these exams.

In the general care of MS patients, physicians and nurses should be cognizant of the following conditions and the implications for the resident with MS:

Menstrual Cycle

Sometimes symptoms such as fatigue and numbness may increase in patients with MS just before menses and improve as the flow begins.

Birth control pills may reduce the ebb and flow of symptoms.

Menopause

In women with MS, as with other women, menopause can cause uncomfortable symptoms.

These can be controlled for some with hormone replacement therapy. Estrogen may be especially helpful in preventing osteoporosis for which women with MS are already at increased risk due to inactivity and steroid use. New studies have offered a new perspective and the risks and benefits of HRT should be discussed carefully with the resident with MS.

Heat and Humidity

Heat aggravates MS symptoms in 80% of patients. 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. 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, as may reduced mobility over the long term. 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 medication is likely to be indicated. Particular care should be taken in transfers and prevention of falls is very important as fractures may occur easily and heal slowly in this population.

Exercise

Some patients 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.

Infections

While infections, e.g., urinary tract infections, 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 with steroids.

Hypothyroidism

This condition can cause slowing down, fatigue, weight gain, slowed thinking, and even neurologic symptoms that may be confused with MS symptoms.

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 MS patients have non-specific pain.

Assessment of pain should consider fibromyalgia and arthritis.

Insomnia

Sleep disturbances are common in the MS population and can exacerbate daytime fatigue.

Sleep disturbances may be related to nighttime muscle spasms, bladder disorders, pain, depression, or other factors.

Obesity

Inactivity secondary to disability and depression may contribute to obesity.

Treating the common health condition of obesity is challenging, as most nursing home residents with MS cannot participate in vigorous exercise. However, exercise as possible, diet, and medication should be considered, as obesity is associated with a number of other serious health disorders. Given the deleterious effects of obesity on independence for many disabled individuals, it is important that the nursing home staff monitor residents' weights and provide a diet that meets nutritional needs but also has the purpose of preventing serious weight gain and obesity.

Immunizations

Recent studies indicate that influenza (flu) vaccination is not associated with a statistically significant increase in the rate of MS attacks or with greater progression of the disease over six months following vaccination.

Having MS should not preclude a resident from having a flu shot or the pneumovax. Flu can be very serious in someone with MS who has compromised respiratory status. Also, 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.

End of Life Issues

As with all nursing home residents, residents with MS must consider and inform family and nursing home staff of their wishes regarding end-of-life should they be unable to make health care decisions for themselves.

Residents and families may be reluctant to discuss these difficult matters in depth, especially when the resident with MS is young or middle aged. Nonetheless, the resident should define their wishes clearly so that family and staff understand what measures to take or avoid regarding end of life care. When quality of life seems to deteriorate for very advanced residents, they may express a wish to die, discontinue treatment, refuse nutrition or engage in risky behaviors. It is important that staff understand the best ways to discuss such matters with the resident and/or bring in other professionals as needed (e.g., clergy, psychiatrists, social workers, hospice professionals).

It may be quite appropriate to bring in hospice care for some very sick residents with MS. Hospice professionals are more skilled at 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.

PSYCHOSOCIAL ISSUES

The decision to place an elderly loved one in a nursing home, even a facility of high quality, is always difficult. When the loved one is a younger person with MS, the decision is that much more distressing. Even though caring for a person with severe disability at home often becomes impossible, the psychological ramifications of placing a young–middle aged person into an environment generally geared towards the care of the elderly make the decision troublesome and disturbing for both the family and the individual with MS.

The adjustment to nursing home life for the person with MS is complicated by the ongoing grieving process over the many losses that accompany severe 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.

Generational differences may mean that the individual has different needs and interests than others in the facility, he/she may have young children, a spouse, and/or aging parents and different adjustment issues. An intentional effort to train nursing and other staff in MS care and provide specific age-appropriate programming and adequate space and facilities will make this difficult transition smoother and improve the quality of life for persons with MS. The following recommendations may help address the psychosocial needs of the younger resident with MS:

Activities

Offer age-appropriate and meaningful recreational, social, vocational and leisure activities for residents with MS.

Activities might include: continuing education, computer activities, and volunteer opportunities outside of the nursing home, theater trips, and shopping trips into the community. Social isolation and boredom are common and activities that are appropriate for elders may not meet the needs of younger adults. Working 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 may enhance daily nursing home life for these residents.

Depression

Clinicians should be attentive to signs of depression and offer counseling, consultation with mental health specialists and pharmacologic treatment.

At least 50 percent of people with MS will experience a major depressive episode at some point over the disease course. As a result 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. The nursing home should identify knowledgeable clinicians in the community to whom they can refer depressed patients if this service cannot be provided in-house.

Suicide Risk

Nursing home staff should be trained in identifying signs of severe depression and suicide risk.

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 patients 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.⁴ 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
- appearing 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
- giving things away.

⁴Vberman AL, Samuel L: Suicide among people with multiple sclerosis. *J Neuro Rehab* (1993) 7(2): 53–61.

Spiritual Life

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 them grapple with these issues.

Privacy

Provide opportunities for private interaction with loved ones who visit.

Provide appropriate spaces for visits with spouses and young children. Accommodations that allow opportunities for private sexual expression may also be appropriate for many residents with partners who visit.

DAILY CARE ISSUES

The following recommendations reflect an approach to nursing home life and activities of daily living that resemble a home care model more than a hospital or nursing home model of care. In this model, the resident is expected, as much as possible, to direct and participate in his/her own care. Again, these issues are not exclusive to residents with MS. However, they are especially meaningful for the younger resident.

Staff Assignment

Provide for permanent assignment of direct care staff.

Permanent staffing will facilitate specialized MS skills development in staff and foster meaningful, consistent relationships between staff and residents. (The average length of stay in the nursing home for the resident with MS is considerably longer than the traditional geriatric resident.)

Resident Choice

Offer as much resident choice and independence as possible regarding activities of daily living, e.g., showering schedule, clothing and make-up choices, etc.

While all nursing home residents should be able to exercise choice in their activities of daily living, younger residents often have more defined opinions about such matters as how frequently and when they shower or bathe, what they wear, their food choices, and about personal grooming. Independence may be expressed as accomplishing some tasks alone, making independent choices and directing their care.

Age Appropriate ADLs

Plan for age-related activities of daily living that are not frequently seen in elderly residents.

Age-related ADLs 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 period.

Eating

Facilitate as much independence in eating as possible as self-feeding is often a priority for the resident as is a regular diet in spite of swallowing or chewing difficulties.

Engage a speech therapist and occupational therapist to provide advice regarding positioning during eating, appropriate exercises of oral musculature and other swallowing and self-feeding techniques and adaptive equipment that might be useful.

Transfers

Make lift devices (e.g., Hoyer lifts or track lift systems) and other transfer aids (e.g., transfer belt, sliding board) available to all staff for resident transfers.

Residents with MS often are heavier (they are younger and less frail) and because of MS spasticity, spasms, and paralysis, are usually more dependent in transfers than frail, geriatric residents.

Staff Relationships

Provide sensitivity training to staff regarding appropriate relationships with younger residents.

Staff tend to be closer in age to residents with MS and may identify with them to a greater degree than geriatric residents. This may prove confusing for staff that may develop close friendships with residents. A resident may make sexual overtures to a staff member or may be the target of sexual overtures by staff. The potential for these complex relationship issues in the nursing home setting are not as frequently anticipated in the elderly population. They should be anticipated with a younger population and addressed during staff training.

Cognitive Issues

Provide training for staff regarding potential behavioral and cognitive problems.

An understanding of the emotional responses that may accompany MS as well as the potential for cognitive dysfunction, may help nursing 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 and unpleasant to a nursing assistant during

ADL routines. There may be angry outbursts and 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 nursing assistant be more tolerant of the behavior and identify solutions for better managing the relationship.

REHABILITATION ISSUES

Availability of Rehabilitation Services

For most nursing home residents with MS, rehabilitation services have come to represent more than access to the therapies per se, but rather vital access to mobility and independence. These are precious commodities to those who have been significantly deprived of them because of MS. Rehabilitation services are consistently cited as a high priority for nursing home residents with MS. Therefore, to fully address the needs of this population, rehabilitation must be a primary component of any nursing home program for people with MS.

Reimbursement of rehabilitation services is often problematic and most third party payers require “improvement” to cover rehabilitation services. While these services are crucial to preventing complications and improving comfort and quality of life for these residents, insurers don’t always see it this way.



It is very important for a nursing home with residents who have MS to link with rehabilitation professionals with expertise in MS (e.g., Easter Seals, a local rehabilitation hospital, a local MS Center, a seating clinic). The rehabilitation and assistive technology needs of this population are often complex and difficult to meet without expert advice and consultation.

Seek individual consultations with physiatrists, OTs, PTs, STs, neuropsychologists, psychiatrists, and other appropriate staff (e.g., orthopedists, orthotists, assistive technology experts) to provide support in complex situations and offer a customized approach to assessing mobility, positioning, feeding, and equipment needs as well as to therapeutic exercise and training.

At a very basic level, residents with MS at any nursing facility should have access to rehabilitation professionals who can assess and prescribe equipment and therapeutic activities that address mobility needs (including management of spasticity, positioning, sensory dysfunction, tremors, ataxia, positioning needs), feeding, communication, and swallowing dysfunction, and limitations in performing activities of daily living. OTs, PTs, STs, as well as restorative aides must be available to help residents maximize independence, mobility, and quality of life.

Provide group rehabilitation programs.

Group programs provide the opportunity for socialization and peer support as well as therapeutic exercise (e.g., stretching, range of motion) and skills training (e.g., transfer training, ADL training).

Offer expressive therapies.

Music and art therapies, writing programs, pet therapy, etc. provide opportunities for self-expression and may enhance adjustment to the nursing home setting and to disability, improve attitude and outlook and provide fun, stimulating, and enjoyable activities in which to participate.

Offer speech therapy services to residents with MS.

Communication deficits due to MS include dysarthria, and scanning speech. These deficits may also be seen in geriatric residents, however the communication deficits in MS are unlike those associated with aphasia (stroke). Generally, language is unaffected in MS. Speech and occupational therapists often work together to maximize communication abilities of residents with MS. Some residents may require augmentative communication systems (e.g., speech synthesizers, voice amplification, and letter boards). Many residents would benefit from access to e-mail and the Internet and may be more interested in learning to use these modes of communication than the geriatric population.

Offer consultation with a physiatrist for rehabilitation and physical medicine treatments.

The need for botox injections, phenol blocks, baclofen pump, pain management, positioning, modalities such as ultrasound, TENS, etc. can be assessed, and provided by a physiatrist.

Wheelchairs, Equipment, Physical Environment, and Assistive Technology

Offer multi-disciplinary assessment of wheelchair needs and positioning needs in the wheelchair and bed.

Their younger age and developmental stage in life, generates a great need and desire for mobility to socialize, gain access to the community, participate actively in nursing home-based activities and control their own activities. The nature and extent of MS disability has an impact on the type of wheelchairs needed, as well as the type of wheelchair controls, transfer aids (e.g. lifts), beds and other mobility equipment. Because of severe physical disability (weakness, paralysis, tremors, spasticity, fatigue, sensory deficits, incoordination, visual deficits, etc.), residents with MS frequently require power wheelchairs with tilt and recline capabilities, wide dimensions, customized positioning, and customized drive controls. Residents with MS often require complex drive systems (e.g., breath-controlled, head-controlled, tongue switches, joy sticks) due to weakness, tremors, spasticity, or paralysis generated by

their MS. Most facilities will not have the resources to have such a comprehensive and on-site program. Developing relationships with positioning specialists and wheelchair vendors in the community who can consult as needed is recommended. Proper positioning can improve comfort, independence, and mobility as well as prevent secondary complications such as skin breakdown, postural deformities/contractures, and compromised breathing.

To maximize third party coverage of wheelchairs and other equipment, use experienced rehabilitation professionals to provide documentation of need and specifications for the equipment.

Medicaid, Medicare, and other third party payers may initially refuse coverage of specialized wheelchairs for nursing home residents. It is important to provide appropriate documentation for these claims and to not accept initial refusals as final. Therapists and physiatrists with experience in MS will be able to maximize the possibility of full coverage.

Provide for quick and regular wheelchair maintenance and repair.

Because residents with MS use their wheelchairs frequently and because they often have such symptoms as severe tremors and spasticity, they tend to be “hard” on their wheelchairs, necessitating frequent repairs and regular maintenance. Due to their dependency on their wheelchairs, many residents with MS cannot be without them if they need to be taken off site for repairs and maintenance. They may feel stranded and lost without them for anything but a short period. While many facilities may not be able to provide this service on-site, developing a strong 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 staff training concerning the proper use and cleaning of the wheelchairs, how to charge power chairs and proper use of positioning devices such as splints.

These residents’ wheelchairs are often costly and complex machines that require on-going care and maintenance to remain reliable. Staff should be instructed to clear crumbs and food stains, clean up after episodes of incontinence, and clean up after outdoor use (clearing mud, leaves). Also provide staff training concerning proper positioning, e.g., wearing schedule of splints, checking for skin breakdown or irritation, and proper use of other positioning devices in bed and the wheelchair.

Maximize accessibility of the physical plant.

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. Also, the 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 power wheelchairs and scooters, lifts and other equipment.***
- ◎ ***Charging areas for these power devices must be available.***
- ◎ ***Individually regulated heat and air-conditioning controls in resident rooms are an important environmental feature for residents with MS.*** Most people with MS experience heat intolerance. MS symptoms may temporarily worsen when the individual is exposed to a hot environment, hot shower, or bath, or when they have a fever. MS spasticity may worsen in a cold environment.
- ◎ ***The physical layout should encourage and support socialization and facilitate independence and mobility of residents.*** For example, elevator controls that can be operated independently, accessible lounges and socialization areas, and wide corridors to accommodate large wheelchairs facilitate mobility and socialization.
- ◎ ***This younger population may require greater access to privacy.*** Residents with MS may have young families who visit. Child-friendly (i.e., noise is OK, safe play areas) areas and lounges or rooms where families/spouses can visit (and perhaps stay overnight) can help individuals with MS adjust more effectively to the nursing home.

Offer access to assistive technology for mobility, personal comfort, and intellectual stimulation.

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. Technology can provide stimulation, may counter isolation, promote self-sufficiency and control over the environment, may enhance mental health, and may reduce stress on staff by enabling the resident to perform tasks otherwise performed by nursing assistants and other staff.

Assistive technology often means adapting the user interface, e.g., adding voice activation, breath-controlled switches and phones, head or tongue switches, etc. to existing devices. Personal comfort devices include: adapted nurse call systems, accessible bed controls, and modified controls for heating and air conditioning, lights, and window shades. Intellectual engagement devices include: access to the Internet, e-mail, and computer programs, accessible VCR controls, TV remote control, ham radio controls, CD players or tape machines, telephone, etc.

Other assistive technology devices that may provide benefit to people with MS in nursing homes include accessible/modified door openers and elevator call systems. Environmental control units (ECUs) are coordinated systems of controlling many aspects on the environment through single device. ECUs can operate window shades, television, CD players, lights, phone, etc., all through one accessible control box. These units can enhance quality of life and reduce dependence on staff.

NEUROPSYCHOLOGICAL ISSUES

The cognitive presentation of the resident with MS in nursing homes can be the cause of significant staff misinterpretation of resident behavior and may lead to difficult interpersonal relationships between the staff and resident. Residents with MS are more likely to be cognitively intact compared to other residents.⁵ However, the word “intact” may be misleading. Specific cognitive deficits, such as impaired short-term memory, planning, attention, judgement, and organizational skills are common in MS. They are rarely adequately described in nursing summaries and leave the impression that the resident’s general cognitive performance is unremarkable. The resident with MS may not be a reliable source of information. While he/she may appear credible and cognitively intact, their self-report may in fact, not be reliable. This differs from interactions with residents who have significant dementia where staff would not necessarily expect reliable self-report.

When assessing the cognition of those with MS, one must be careful not to overestimate their cognitive abilities especially given that their language skills usually remain intact along with generally preserved intellectual functioning.

Differentiating between cognitive dysfunction that may occur as a result of normal aging or even a co-morbid disorder and MS deficits is also important. Recommendations on addressing the neuropsychological issues of nursing home residents with MS follow.

Offer assessment of potential cognitive deficits by appropriate, trained neuropsychologists.

Identify neuropsychologists in the community, to whom to refer residents for assessment. Some residents with MS may benefit from cognitive remediation.

Provide training to staff in recognizing and responding to residents with cognitive deficits.

Sensitivity and awareness of the neuropsychological and emotional issues that may influence the behavior of the resident, can help staff manage these behaviors more effectively with the following strategies:⁶

- ⊙ Organize the environment so that items used regularly remain in familiar places.
- ⊙ Develop a consistent daily routine.
- ⊙ Plan activities requiring mental effort early in the day, and limit them to a short time period.
- ⊙ Conduct conversations in quiet places to minimize distractions.

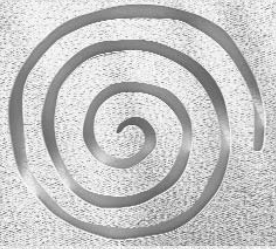
⁵Buchanan RJ, op. cit.

⁶Adapted from E-quipping Lesson Plan in MS, 2001.

- ⊙ Repeat information and write down important points.
- ⊙ Follow verbal instructions with written back up and visual aids when possible.
- ⊙ Introduce change slowly, one step at a time. Work on one task at a time.
- ⊙ Encourage the person to keep a notebook, electronic organizer, or calendar to track important information.
- ⊙ Provide a quiet environment for activities that require more mental activity.

Consider cognitive status when conducting a wheelchair assessment.

Judgement, planning and organizational functions will have an impact on the safety of the resident (and those in their path). It is important that these factors be considered when deciding on controls mechanisms and type of wheelchair.



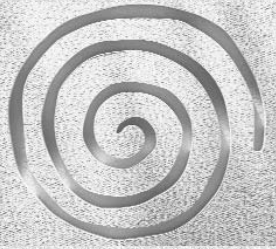
The Nursing Home Admission Process

As your staff develops experience and expertise caring for this unique resident population, you may find that you receive more and more referrals for admission. Applying your experience to helping potential residents prepare for admission will be beneficial to the staff at your facility as well as to the individual, his/her family and the facility. Planning for nursing home placements is complex and laden with a variety of emotional issues. However, if families give some thought and attention to this process, it will be to everyone's benefit. Here are some issues to encourage the individual and family to consider in preparation for admission:

- ◎ **Financial Planning:** Careful evaluation of existing financial resources for nursing home care may require the services of a certified financial planner (listings are available through the Securities and Exchange Commission). Encourage the family to contact the state office responsible for funding nursing home care (Medicaid) and request a copy of the application and eligibility requirements to help clarify the documents needed and the time frame for submission. In addition, expenditure of funds on items deemed "appropriate" under eligibility guidelines can be determined.
- ◎ **Designation of Health Care Proxy and Advanced Directives:** As you know, federal regulations in force since 1991 require health care institutions to offer an opportunity to designate a person or persons who will direct medical care in the event the potential resident is unable to do so as determined by a physician. Decisions of this nature are difficult given the subject matter but it is important that the family engage in discussions about resuscitation, artificial feeding, mechanical ventilation, treatment with antibiotics, etc. prior to admission.
- ◎ **Pre-admission Assessments:** Providing information about health problems, preferences and needed care to clinical staff at the facility in advance of admission will help staff to prepare. Ask families to gather detailed information about

all care providers including contact numbers, details about diagnosis, completed physician's examination form with up to date assessments and information about hospitalizations, current treatment and medication regimens.

- ◎ **Equipment:** Obtaining necessary medical equipment prior to admission may be smoother than ordering it once the individual is a nursing home resident. Anticipating the need for a specialized wheelchair or seating equipment, for instance, may forestall problems in gaining approval after nursing home admission.
- ◎ **Emotional Preparation:** Encourage families to communicate openly with one another about the difficult transition ahead, seeking professional counseling, if necessary. Doing so may result in a smoother transition, minimizing the guilt, anger resistance, and sadness often associated with this decision.



Training Materials and Resources

THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

The National Multiple Sclerosis Society's mission is to end the devastating effects of MS. Through its fifty-state network of chapters, the Society funds research, furthers education, advocates and provides a variety of empowering programs for the approximately 400,000 Americans who have MS and their families.

The National Multiple Sclerosis Society was founded in 1946. Sylvia Lawry, an extraordinary ordinary citizen whose brother suffered from the disease, placed a classified advertisement in *The New York Times* asking to hear from anyone who had recovered from MS. However, all of the letters she received came from others who also sought help and hope. Instead of being discouraged, Ms. Lawry mobilized a group of friends and advisors, including some who had answered her ad. From this the National Multiple Sclerosis Society was formed to promote contacts among neurologists around the country who treated MS and to raise money to fund a search for answers.

Today, the National Multiple Sclerosis Society supports more MS research, educates more healthcare professionals and serves more people with MS than any national voluntary MS organization in the world and is the only national voluntary MS organization that meets the standards of ALL major agencies that rate not-for-profit groups.

Across the country, the National Multiple Sclerosis Society has 2,700 volunteer leaders and over a million more volunteers to carry out its mission to end the devastating effects of MS. The Society has over 600,000 general members, including 280,000 who have MS. The Society's revenue is a combination of private donations, membership dues and contributions, legacies and bequests, and fund-raising events.

Programs Offered by the NMSS

The National Multiple Sclerosis Society, through its chapters across the country, offers a wide range of programs and support services to people with MS. The Society also serves as an advocate for disability rights, improvements in health-care delivery, access to adequate, affordable health insurance and long-term care, and federal funding of MS-related research. Many of these activities directly relate to the need for long-term care services and information. Society efforts include:

Comprehensive information and referral programs

Each chapter maintains a database of resources and information pertaining to all aspects of multiple sclerosis and services available in the community to meet the many needs generated by the disease.

Education

Chapters offer programs on all aspects of MS for people with MS, family caregivers, and health care professionals. Programs for people with MS and families emphasize the value of self-advocacy and empowerment in directing their MS care.

Self-help groups and counseling programs

These are offered to help people with MS and families cope with the day-to-day challenges of living with the emotional demands of this chronic, unpredictable and often disabling disease. There are over 2000 Society-affiliated support groups across the United States.

Caregiver supports

The Society recognizes that informal caregivers—unpaid family, friends, and neighbors—provide the majority of long-term care. Educational and support programs are offered by many chapters to help caregivers attend to their own emotional needs as well as learn how to best care and advocate for their loved one with MS.

Family programs

The Society offers a variety of programs that bring families together for education, emotional support, and/or social activities. These programs are offered in recognition of the fact that MS affects each member of the family uniquely and generates different needs for each.

Advocacy

The Society is a preeminent voice for people with disabilities who require access to the range of affordable, quality, and age-appropriate long-term care services. Through our chapters and national government affairs office in Washington, D.C., our advocates have a say in such long-term care issues as the Medicare and Medicaid programs, policies regulating nursing home care, assisted living, independent living programs, insurance and more on a federal, state, and local level.

Research

The Society supports a wide range of clinical and scientific research in MS. In addition, research in health services and policy provides data to support our advocacy work and helps identify and document the unique long-term care and health management needs of our constituents.

Specific long-term care programs

Many of our chapters collaborate with long-term care providers to develop and offer specialized long-term care programs for people with MS in their communities. For example, several specialized MS adult day care programs and specialized MS nursing home programs are offered across the country. A number of MS care management, respite care programs and MS assisted living programs have also been developed.

To reach your NMSS chapter call 1-800-FIGHT MS (1-800-344-4867).

Collaboration with Local NMSS Chapters

The National Multiple Sclerosis Society encourages its chapters to collaborate with local agencies and organizations to have age-appropriate, affordable, and high quality long-term care programs available to people with MS in their community. NMSS chapters are not encouraged to own or manage these programs, rather, they are encouraged to work with community providers to advocate for and support the development of these programs. Potential benefits to you of such collaboration include the following:

- Ⓞ Access to expertise and experience of the NMSS in serving people with MS;
- Ⓞ In-service training for your staff;

- ⊙ Possibility of financial support from the chapter for discrete services or program elements;
- ⊙ Assistance in identifying services and professionals in the community who can meet the complex needs of your residents when they exceed the capacity of the nursing home.

Professional Resource Center: 1-866-MS-TREAT (1-866-678-7328)

The Professional Resource Center (PRC) is a comprehensive resource for health care professionals offering information, continuing education, consultation with multi-disciplinary experts and publications. The PRC houses the most comprehensive library of MS information in the world and hosts a comprehensive Web site for health care professionals. Through its consultation program, professionals may consult with experts in a variety of fields about disease management, health insurance, long term care, the development of MS specialty clinics, and more. <http://www.nationalmssociety.org/PRC.asp>

Nursing Home Task Force

The Nursing Home Task Force, author of this document, was created to identify the unique needs of people with MS who reside in nursing homes and advocate for programs and funding that meet those needs. The task force operates under the auspices of the Long-Term Care Subcommittee of the NMSS Medical Advisory Board and is staffed by Dorothy Northrop. Ms. Northrop can be reached at 212-476-0454 or dorothy.northrop@nmss.org.

PARALYZED VETERANS OF AMERICA (PVA)

The PVA is a congressionally chartered veteran's service organization dedicated to the special needs of veterans with spinal cord dysfunction. A significant number of PVA members have multiple sclerosis. PVA services include research and education, programs for professionals, and publications. <http://www.pva.org>

MS Clinical Practice Guidelines

The PVA publishes clinical practice guidelines developed by the Multiple Sclerosis Council:

- ⊙ ***Disease Modifying Therapies in Multiple Sclerosis*** is available at:
http://www.pva.org/NEWPVASITE/publications/pubs/msdmt_cpg.htm

- ◎ **Fatigue and Multiple Sclerosis** is available at: <http://www.pva.org/NEWPVASITE/publications/pubs/mscpg.htm>
- ◎ **Urinary Dysfunction and Multiple Sclerosis** is available at: <http://www.pva.org/NEWPVASITE/publications/pubs/urinarycpg.htm>
- ◎ **Immunizations in MS** is available at: http://www.pva.org/NEWPVASITE/publications/pubs/ms_immuniz.htm
- ◎ **Spasticity and MS** (upcoming)

MS TRAINING MATERIALS

You may access a number of helpful MS training materials to provide in-service education for your staff. The following materials contain curricula and other resources for teaching your nursing home staff about MS. Contact your local chapter of the National MS Society (1-800-FIGHT-MS) to obtain additional information and to inquire as to whether a NMSS staff person could visit your facility and provide in-service training.

- ◎ **Multiple Sclerosis Training in Your Long Term Care Facility:** This is a curriculum developed by the NMSS for nursing home nursing staff. Two tracks are provided, one for nursing assistants and one for nurses. Teaching outlines, post-lesson quizzes and other materials are provided. Obtain this resource from your local chapter of the NMSS by calling 1-800-FIGHT-MS.
- ◎ **E-quipping MS Lesson Plan:** This is a one-hour MS in-service lesson plan, targeted to nursing assistants. It includes handouts and a post-test. It was developed and is distributed by E-quipping: *AssistED*, *AideED*, *HomeHealthED*. Call 1-888-424-7003 for information on how to obtain.
- ◎ **Multiple Sclerosis: A Course for Occupational and Physical Therapists:** This training kit is targeted to occupational and physical therapists who care for people with MS. The kit offers a training script, slides, and other resource materials and covers treatment strategies and information about rehabilitation and MS. Call the NMSS Professional Resource Center to find out more about the kit.

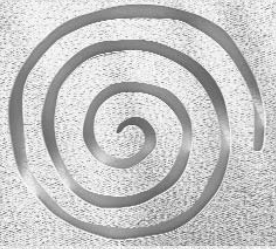
MODELS OF SPECIALIZED NURSING HOME CARE

The following nursing homes offer specialized programming for residents with MS. They may be a good resource for you and your staff regarding clinical and administrative issues of caring for this unique population.

- ◎ **The Boston Home:** 617-825-3905. In this 84-bed facility in Boston, MA about 90% of the residents have MS. Founded in 1881, the Boston Home offers a staff to resident ratio of 4:6. Rehab services are provided, and an adaptive computer/assistive technology lab is

available to residents. A seating program, network of medical and psychology consultants, staff training and career ladders, a volunteer program, and a program of age-appropriate trips and activities are unique features of the Boston Home program. Most residents with MS are between the ages of 30 and 60 and average length of stay is about 8 years.

- ◎ **Beechwood Home:** 513-321-9294. This 88-bed facility, located in Cincinnati, Ohio was founded in 1890 and provides residence for people with chronic, physical disabilities. The average age of residents is 58 years old. The facility maintains a high staff-resident ratio and offers age-appropriate activities, assistive technology and a computer program, rehabilitation, and family events.
- ◎ **Inglis House:** 215-878-5600. This 297-bed facility, located in Philadelphia, PA was chartered in 1877 and offers a unique continuum of long-term care programs for people with physical disabilities 17 years of age and older. Approximately one-third of the nursing facility residents have multiple sclerosis. All rooms are single rooms in the nursing facility. Also on campus are an adult day health program, seating and positioning program, a durable medical equipment program, and independent-living apartments where residents hire personal care assistants and manage their own care independently. Inglis House also offers apartments off-campus. The nursing home residence offers an in-house vocational program, transition to independence program, computers, GED and other learning opportunities and a number of other age-appropriate, innovative activities for its residents.
- ◎ **Other Facilities:** Other facilities have developed specialized MS “wings” or specialized programming for residents with MS. Contact your local chapter of the NMSS at 1-800-FIGHT-MS to see if there is a facility in your area that is providing this specialized type of programming.



Medications Commonly Used in MS

Note: This appendix is reprinted with permission from *Multiple Sclerosis: The Questions You Have; The Answers You Need*. Kalb, Rosalind (ed.), New York: Demos Medical Publishing, 2000. It is also available on the Web site of the National MS Society (www.nationalmssociety.org) in the Treatments section.

Many of these medications may meet the definition of a “Drug Used Out of Class”—in other words, a medication that was approved by the FDA for a different disorder. The MS nurse in the long-term care facility (or other appropriate personnel) needs to review this section of the guidelines and institute the appropriate consent forms required on the record. In addition, these drugs may raise issues on record and billing audits since the diagnosis normally associated with the drug will not be listed for this resident. It is important that the documentation in the records clearly identifies why the drug is being used to avoid payment denials.

TABLE OF MEDICATIONS COMMONLY USED IN MS

Generic Name	Brand Name ^a	Usage in MS
Alprostadil	Prostin VR	Erectile dysfunction
Alprostadil	Muse	Erectile dysfunction
Amantadine		Fatigue
Amitriptyline	Elavil	Pain (paresthesias)
Baclofen	Lioresal	Spasticity
Bisacodyl ^b	Dulcolax	Constipation
Bupropion	Wellbutrin	Depression
Carbamazepine	Tegretol	Pain (trigeminal neuralgia)
Ciprofloxacin	Cipro	Urinary tract infections

^aAvailable in US and Canada unless otherwise noted.

^bAvailable without a prescription.

Table continued on next page

TABLE OF MEDICATIONS COMMONLY USED IN MS (cont'd)

Generic Name	Brand Name ^a	Usage in MS
Clonazepam	Klonopin (US); Rivotril (Can)	Tremor; Pain; Spasticity
Dantrolene	Dantrium	Spasticity
Desmopressin	DDAVP Nasal Spray	Urinary frequency
Diazepam	Valium	Spasticity (muscle spasms)
Docusate ^b	Colace	Constipation
Docusate mini enema ^b	Therevac Plus (US)	Constipation
Fluoxetine	Prozac	Depression; Fatigue
Gabapentin	Neurontin	Pain
Glatiramer acetate	Copaxone	Disease modifying agent
Glycerin ^b	Sani-Supp suppository (US)	Constipation
Imipramine	Tofranil	Bladder dysfunction; Pain
Interferon beta-1a	Avonex	Disease modifying agent
Interferon beta-1a	Rebif (Canada)	Disease modifying agent
Interferon beta-1b	Betaseron	Disease modifying agent
Isoniazid	Laniazid; Nydrazid	Tremor
Magnesium hydroxide ^b	Phillips' Milk of Magnesia	Constipation
Meclizine	Antivert (US); Bonamine (Can)	Nausea; Vomiting; Dizziness
Methenamine	Hiprex, Mandelamine (US); Hip-rex, Mandelamine (Can)	Urinary tract infections (preventative)
Methylprednisolone	Depo-Medrol	Acute exacerbations
Mineral oil ^b		Constipation
Mitoxantrone	Novantrone	Disease modifying agent
Modafinil	Provigil	Fatigue
Nitrofurantoin	Macrochantin	Urinary tract infections
Nortriptyline	Pamelor	Depression
Oxybutynin	Ditropan	Bladder dysfunction
Oxybutynin (extended release formula)	Ditropan XL	Bladder dysfunction
Papaverine		Erectile dysfunction
Paroxetine	Paxil	Depression
Pemoline	Cylert	Fatigue

^aAvailable in US and Canada unless otherwise noted.

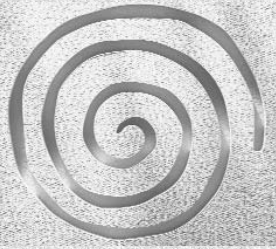
^bAvailable without a prescription.

TABLE OF MEDICATIONS COMMONLY USED IN MS (cont'd)

Generic Name	Brand Name ^a	Usage in MS
Phenazopyridine	Pyridium	Urinary tract infections (symptom relief)
Phenytoin	Dilantin	Pain (dysesthesias)
Prazosin	Minipress	Bladder dysfunction
Prednisone	Deltasone	Acute exacerbations
Propantheline bromide	Pro-Banthine	Bladder dysfunction
Psyllium hydrophilic mucilloid ^b	Metamucil	Constipation
Sertraline	Zoloft	Depression
Sildenafil	Viagra	Erectile dysfunction
Sodium phosphate ^b	Fleet Enema	Constipation
Sulfamethoxazole	Bactrim; Septra	Urinary tract infections
Tamsulosin	Flomax	Bladder dysfunction
Terazosin	Hytrin	Bladder dysfunction
Tizanidine	Zanaflex	Spasticity
Tolterodine	Detrol (US)	Bladder dysfunction
Venlafaxine	Effexor	Depression

^aAvailable in US and Canada unless otherwise noted.

^bAvailable without a prescription.



Recommended Resources

GENERAL READINGS

Demos Medical Publishing, New York, NY (tel: 800-532-8663)

Bowling A. *Alternative Medicine and Multiple Sclerosis*. 2001.

Burks J, Johnson K (eds.). *Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation*. 2000.

Coyle P, Halper J. *Meeting the Challenge of Progressive Multiple Sclerosis*. 2001.

Halper J, Holland N (eds.). *Comprehensive Nursing Care in Multiple Sclerosis* (2nd ed.). 2002.

Holland N, Murray TJ, Reingold SC. *Multiple Sclerosis: A Guide for the Newly Diagnosed*. 1996, (available in Spanish).

Kalb R. *Multiple Sclerosis: A Guide for Families*. 1998

Kalb R. *Multiple Sclerosis: The Questions You Have—The Answers You Need* (2nd ed.). 2000, (available in Portuguese).

Kraft GH, Catanzaro M. *Living with Multiple Sclerosis: A Wellness Approach* (2nd ed.). 2000.

Perkins L, Perkins S. *Multiple Sclerosis: Your Legal Rights*. 1999.

Rumrill PD (ed.). *Employment Issues and Multiple Sclerosis*. 1996.

Schapiro RT. *Symptom Management in Multiple Sclerosis* (3rd ed.). 1998.

Schwarz SP. *300 Tips for Making Life with Multiple Sclerosis Easier*. 1999.

Van den Noort S, Holland N. *Multiple Sclerosis in Clinical Practice*. 1999.

Additional Recommendations

- Cohen MD. (1996). *Dirty Details: The Days and Nights of a Well Spouse*. Philadelphia: Temple University Press.
- Holland N, Halper J (eds.). (1998). *Multiple Sclerosis: A Self-Care Guide to Wellness*. Washington, D.C.: Paralyzed Veterans of America.
- James JL. (1993). *One Particular Harbor: The Outrageous True Adventures of One Woman with Multiple Sclerosis Living in the Alaskan Wilderness*. Chicago: Noble Press.
- Koplowitz A., Celizic M. (1997). *The Winning Spirit: Lessons Learned in Last Place*. New York: Doubleday.
- Kroll K, Klein EL. (1995). *Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled*. Bethesda, MD: Woodbine House.
- LeMaistre J. (1994). *Beyond Rage: Mastering Unavoidable Health Changes*. Dillon, CO: Alpine Guild.
- MacFarlane EB, Burstein P. (1994). *Legwork: An Inspiring Journey Through a Chronic Illness*. New York: Charles Scribner's Sons.
- Olkin R. (1999) *What Psychotherapists Should Know About Disability*. New York: Guilford Publications.
- Pitzele SK. (1986). *We Are Not Alone: Learning to Live with Chronic Illness*. New York: Workman.
- Resources for Rehabilitation. (1993). *Resources for People with Disabilities and Chronic Conditions*. Lexington, MA: Resources for Rehabilitation.
- Resources for Rehabilitation. (1994). *A Woman's Guide to Coping with Disability*. Lexington, MA: Resources for Rehabilitation.

INFORMATION FROM THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Books for Healthcare Professionals

Multiple Sclerosis: A Focus on Rehabilitation.
Multiple Sclerosis: A Model of Psychosocial Support.
Multiple Sclerosis: The Nursing Perspective.
Multiple Sclerosis: Pharmacologic Management.

Booklets for Lay Audiences

(Available from the local chapter [800-FIGHT-MS, select option 1], or on the Web site [www.nationalmssociety.org] in the Library section.)

Living with MS—ES 0087
What Everyone Should Know About Multiple Sclerosis—ER 100
Research Directions in Multiple Sclerosis—ES 6017
ADA and People with MS—ECS 6021
The Win-Win Approach to Reasonable Accommodations: Enhancing Productivity on Your Job—ES 6025
Managing MS Through Rehabilitation—ECS 6022
Controlling Spasticity—ECS 6037
Stretching for People with MS—ES 6041 (not available on Web site)
Stretching with a Helper for People with MS—ES 6042 (not available on the Web site)
Exercise as Part of Everyday Life—ES 6008
Fatigue: What You Should Know—ES 6046
Food for Thought: MS and Nutrition—ES 6020
Multiple Sclerosis and Your Emotions—ES 6007
Taming Stress in Multiple Sclerosis—ES 6034
At Home with MS: Adapting Your Environment—ECS 6035
Solving Cognitive Problems—ECS 6029
Controlling Bladder Problems in MS—ES 0039
Understanding Bowel Problems in MS—ECS 6036
PLAIN TALK: A Booklet About MS for Families—ECS 55
Someone You Know Has MS: A Book for Families—ES 0045
When a Parent Has MS: A Teenager's Guide—ECS 6024
A Guide for Caregivers—ES 6010
Clear Thinking About Alternative Therapies—ECS 6038

Materials Available in Spanish

Hacia una Comprensión de los Problemas de la Vejiga en la Esclerosis Múltiple

Lo que Todo el Mundo Debe Saber sobre la Esclerosis Múltiple

Qué es la Esclerosis Múltiple?

Qué le Interesa Conocer sobre la Esclerosis Múltiple?

Sobre la Conservación de Energía

Sobre la Fatiga

Sobre los Problemas Sexuales que no Mencionan los Médicos

Sobre el Diagnóstico: Atando Los Cabos de una Larga Historia . . .

Other MS Society Publications

The History of Multiple Sclerosis (reprint)—Loren Rolak, M.D.

Inside MS—a 32-page magazine for people living with MS published three times yearly

Knowledge Is Power—a series of articles for individuals newly diagnosed with MS

Living Well with MS—a series of workbooks written for, and by, people who have been living with MS for some time.

Keep S'myelin—a quarterly newsletter for young children who have a parent with MS.

WEB SITES

Note: Please be aware that Web site URLs are subject to change without notice.

ABLEDATA

Information on Assistive Technology

<http://www.abledata.com>

Allsup, Inc.

Assists Individuals Applying for Social Security Disability Benefits

<http://www.allsupinc.com>

Apple Computer Disability Resources

<http://www.apple.com/education/k12/disability>

Ares-Serono Group/Rebif

<http://www.serono.com>

Berlex/Betaseron

<http://www.betaseron.com>

Biogen/Avonex

<http://www.biogen.com>

CenterWatch Clinical Trials Listing Service™

<http://www.centerwatch.com>

CLAMS—Computer Literate Advocates for Multiple Sclerosis

<http://www.clams.org>

Consortium of Multiple Sclerosis Centers

<http://www.ms-care.org>

IBM Special Needs Systems

<http://www.austin.ibm.com/sns>

Infosci

Selected Links on MS

<http://www.infosci.org>

International Journal of MS Care

<http://www.ms-care.com>

Medicare Information

<http://www.medicare.gov>

Microsoft Accessibility Technology for Everyone

<http://www.microsoft.com/enable>

Multiple Sclerosis Information Gateway

Schering AG, Berlin, Germany

<http://www.ms-gateway.com>

Multiple Sclerosis International Federation

<http://www.ifmss.org.uk>

The Multiple Sclerosis Society of Canada

<http://www.mssociety.ca>

The Myelin Project

<http://www.myelin.org>

National Family Caregivers Association

<http://www.nfcacares.org>

National Institute of Neurological Disorders and Stroke

<http://www.ninds.nih.gov>

National Library of Medicine

<http://www.nlm.nih.gov>

National Multiple Sclerosis Society

<http://www.nationalmssociety.org>

National Organization for Rare Disorders

<http://www.rarediseases.org>

NARIC—The National Rehabilitation Information Center

<http://www.naric.com>

Rocky Mountain MS Center

Web site on alternative/complementary medicine (CAM)

<http://www.ms-cam.org>

Teva Pharmaceutical Industries Ltd./Copaxone

<http://www.copaxone.com>

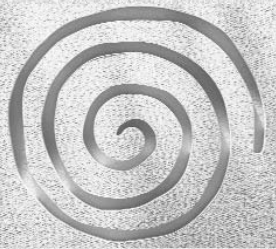
ORGANIZATIONS

- ◎ **Consortium of Multiple Sclerosis Centers (CMSC)** (c/o Gimbel MS Center at Holy Name Hospital, 718 Teaneck Road, Teaneck, NJ 07666; tel: 201-837-0727; Internet: www.ms-care.org). The CMSC is made up of numerous MS centers throughout the United States and Canada. The Consortium's mission is to disseminate information to clinicians, increase resources and opportunities for research, and advance the standard of care for multiple sclerosis. The CMSC is a multidisciplinary organization, bringing together health care professionals from many fields involved in MS patient care.
- ◎ **Department of Veterans Affairs (VA)** (810 Vermont Avenue, N.W., Washington, D.C. 20420; tel: 202-273-5400; Internet: www.va.org). The VA provides a wide range of benefits and services to those who have served in the armed forces, their dependents, beneficiaries of deceased veterans, and dependent children of veterans with severe disabilities.
- ◎ **Equal Employment Opportunity Commission (EEOC)** (Office of Communication and Legislative Affairs, 1801 L Street, N.W., 10th Floor, Washington, D.C. 20507; tel: 800-669-3362 (to order publications); 800-669-4000 (to speak to an investigator; 202-663-4900; Internet: www.eeoc.gov). The EEOC is responsible for monitoring the section of the ADA on employment regulations. Copies of the regulations are available.
- ◎ **United Spinal Association** (75-20 Astoria Boulevard, Jackson Heights, NY 11370; tel: 718-803-3782; Internet: www.epva.org). United Spinal Association is a private, nonprofit organization dedicated to serving the needs of its members as well as other people with disabilities. While offering a wide range of benefits to member veterans with spinal cord dysfunction (including hospital liaison, sports and recreation, wheelchair repair, adaptive architectural consultations, research and educational services, communications, and library and information services), they will also provide brochures and information on a variety of subjects, free of charge to the general public.

- ⊙ **Health Resource Center for Women with Disabilities** (Rehabilitation Institute of Chicago, 345 East Superior Street, Chicago, IL 60611; tel: 800-354-7342; Internet: www.rehabchicago.org). The Center is a project run by and for women with disabilities. It publishes a free newsletter, “Resourceful Women,” and offers support groups and educational seminars addressing issues from a disabled woman’s perspective. Among its many educational resources, the Center has developed a video on mothering with a disability.
- ⊙ **International Organization of Multiple Sclerosis Nurses (IOMSN)** (P.O. Box 450, Teaneck, NY 07666; tel: 201-384-2752; fax: 201-384-3954; e-mail: iomsn@aol.com; Web site: www.iomsn.org). An organization of licensed nurses whose professional interests and activities are related to the care of people with multiple sclerosis either through direct practice, research, education, or administration.
- ⊙ **Multiple Sclerosis Society of Canada** (250 Bloor Street East, Suite 1000, Toronto, Ontario M4W 3P9, Canada; tel: 416-922-6065; in Canada: 800-268-7582; Internet: www.mssoc.ca). A national organization that funds research, promotes public education, and produces publications in both English and French. They provide an “ASK MS Information System” database of articles on a wide variety of topics including treatment, research, and social services. Regional divisions and chapters are located throughout Canada.
- ⊙ **National Council on Disability (NCD)** (1331 F Street, N.W., Suite 850, Washington, D.C. 20004; tel: 202-272-2004; Internet: www.ncd.gov). The Council is an independent federal agency whose role is to study and make recommendations about public policy for people with disabilities. Publishes a free newsletter, “Focus.”
- ⊙ **National Family Caregivers Association (NFCA)** (10400 Connecticut Ave., Suite 500, Kensington, MD 20895; tel: 301-942-6430; Internet: www.nfcacares.org). NFCA is dedicated to improving the quality of life of America’s 18,000,000 caregivers. It publishes a quarterly newsletter and has a resource guide, an information clearinghouse, and a toll-free hotline: 800-896-3650.
- ⊙ **National Multiple Sclerosis Society (NMSS)** (733 Third Avenue, New York, NY 10017; tel: 800-FIGHT MS; Internet: www.nmss.org). The NMSS is a nonprofit organization that supports national and international research into the prevention, cure, and treatment of MS, and partners with the healthcare community to enhance quality care. The Society’s goals include provision of nationwide services to assist people with MS and their families, and provision of information to those with MS, their families, professionals, and the public. The programs and services of the Society promote knowledge, health, and independence while providing education and emotional support:

- ⊙ Toll-free access to the local chapter by calling 1-800-FIGHT MS for up-to-date information and referrals.
- ⊙ Web site with updated information and educational programs for lay audiences and professionals about treatments, research, and programs (<http://www.nationalmssociety.org>); local home page in many areas.
- ⊙ Professional Resource Center (tel: 1-866-MS-TREAT; email: MD_info@nmss.org, HealthProf_info@nmss.org) for healthcare professionals involved in the care of people with MS and their families. www.nationalmssociety.org/PRC.asp
 - ⊙ Professional Information and Library Services—information about MS and its management, access to the largest collection of MS-related materials available in a single site, and library/literature search services.
 - ⊙ Information about insurance and long-term care for people with MS
 - ⊙ Continuing education programs.
 - ⊙ Consultation on the development of National MS Society-affiliated clinical facilities.
- ⊙ Knowledge Is Power self-study program (serial mailings) for people newly diagnosed with MS and their families, available through local chapters.
- ⊙ MS Learn Online, a (live and archived) online education series for people with MS and their families, available on the NMSS Web site.
- ⊙ Printed materials available on a variety of topics from the local chapter.
- ⊙ Educational programs on various topics throughout the year, provided through the local chapter.
- ⊙ Annual national teleconference at over 500 sites throughout the United States; call the chapter for the location nearest you.
- ⊙ Wellness programs in some chapters.
- ⊙ **Office on the Americans with Disabilities Act** (Department of Justice, Civil Rights Division, P.O. Box 66118, Washington, D.C. 20035; tel: 202-514-0301; www.usdoj.gov/crt/ada/adahom1.htm). This office is responsible for enforcing the ADA. To order copies of its regulations, call 202-514-6193.
- ⊙ **Paralyzed Veterans of America (PVA)** (801 Eighteenth Street N.W., Washington, D.C. 20006; tel: 800-424-8200; Internet: www.pva.org). PVA is a national information and advocacy agency working to restore function and quality of life for veterans with spinal cord dysfunction. It supports and funds education and research and has a national advocacy program that focuses on accessibility issues. PVA publishes brochures on many issues related to rehabilitation.

- © **Social Security Administration** (6401 Security Boulevard, Baltimore, MD 21235; tel: 800-772-1213; Internet: www.ssa.gov). Application for social security benefits based on disability is through local social security branch offices. The Office of Disability within the Social Security Administration publishes a free brochure entitled "Social Security Regulations: Rules for Determining Disability and Blindness."
- © **Through the Looking Glass: National Research and Training Center on Families of Adults with Disabilities** (2198 Sixth Street, Suite 100, Berkeley, CA 94710; tel: 800-644-2666; fax: 510-848-4445; Internet: www.lookingglass.org).
- © **Well Spouse Foundation** (30 East 40th St., PH, New York, NY 10016; tel: 212-685-8815; 800-838-0879; email: wellspouse@aol.com; Web site: www.wellspouse.org). An emotional support network for people married to or living with a chronically ill partner. Advocacy for home health and long-term care and a newsletter are among the services offered.



Index

- accessibility, 25, 32–33
- activities of daily living, 27–28, 30
- activities, social and educational, 25
- acupuncture, 19
- addiction, 19
- ADLs, 27–28, 30
- admission to nursing home, 37–38
- advanced directives, 37
- advocacy, 40–41
- age-related issues, 9, 15, 24–25, 28–29, 31, 41
- arthritis, 23
- assistive technology, 9, 16, 28, 30–31, 33

- balance, 7
- beds, 18, 31–33
- billing issues, 30, 32, 37–38, 45
- bladder dysfunction, 12–13, 17, 23, 43, 46, 47.
 See also urinary tract
- bowel dysfunction, 11–12
- breathing. *See* respiration

- cancer screening, 20
- caregivers, 40
- cataracts, 9, 18
- catheterization, 12–13, 17
- children, 25, 27, 33. *See also* family issues
- choice regarding care and activities, 28
- choking, 14
- cholesterol testing, 20
- cognition, 1, 15, 17, 34–35
 strategies for coping with cognitive impairment, 34–35

- concentration, 15, 26
- confusion, 16
- constipation, 11, 45–46
- contracture, 6
- coordination, 31
- counseling, 26, 38, 40

- death, 24, 26
- dementia, 15
- depression, 8, 23–24, 26, 45–47
- diarrhea, 11
- disease modification, 3, 42, 46
- dizziness, 46
- drugs. *See* medications and supplements
- dysarthria, 31
- dysphagia, 14, 19

- eating, 8, 28
- end of life issues, 24
- epilepsy, 16
- erectile dysfunction, 45–47
- exacerbation of MS, 16, 46–47
- exercise, 6–8, 10, 22–23, 30
- expressive therapy, 31

- family issues, 15, 24–25, 27, 33, 37–38, 40
- fatigue, 6, 8–9, 14, 21, 23, 26, 31, 43, 45–46
- feeding, 10, 14, 28
- feet, 10, 19
- fever, 8, 12, 20
 and exacerbation of MS, 17, 22, 24, 33
- fibromyalgia, 23

financial issues, 32, 37–38
 flu. *See* influenza
 fluid intake, 11, 13–14, 17
 foot pain, 10, 19

 gait disturbance, 7
 group programs, 15, 30, 41

 health care proxy, 37
 health screening, 20–21
 hearing, 20
 heat, 8, 21–22, 33
 hospice care, 19, 24
 humidity, 21
 hydration, 8
 hypertonia, muscle. *See* spasticity
 hypophonia, 16
 hypothyroidism, 23

 immunization, 16, 24, 43
 incontinence, 10, 12, 17
 independence, 23, 28, 30, 32–33, 41
 infection, 8, 20, 22
 and exacerbation of MS, 16, 22
 influenza, 16, 20, 24
 insomnia, 23
 instability, trunk, 6–7
 intelligence, 15

 language skills, 15, 31, 34
 L'Hermitte's sign, 10
 lift devices, 6–7, 29, 31

 malnutrition, 14
 mammography, 20–21
 meals, 8
 medications and supplements. *Note:* Medications and supplements discussed in the text are listed below. *See also* the Table of Medications Commonly Used in MS, 45–47
 amantadine, 8
 anesthetic, topical, 10, 19
 anti-convulsants, 16, 19
 anti-inflammatories, 20
 antibiotics, 17
 anticholinergics, 12
 antidepressants, 19, 26
 antispastics, 19
 Avonex®, 3
 baclofen, 6
 baclofen, intrathecal, 6, 31
 Betaseron®, 3
 birth control pills, 21
 botulinum toxin, 6, 31
 bulk formers, 11
 clonazepam, 7
 Copaxone®, 3, 20
 corticosteroids, 9, 18, 22
 cranberry extract, 13
 dantrolene sodium, 6
 Detrol, 12
 diazepam, 6
 Ditropan XL, 12
 estrogen, 21
 fluoxetine, 8
 glatiramer acetate, 20
 hormone replacement therapy, 21
 hydroxyzine, 7
 interferon, 20
 isoniazide, 7
 laxatives, 11
 lidocaine, 19
 methylphenidate, 8
 modafinil, 8
 narcotics, 19
 neurontin, 10
 non-steroidal anti-inflammatory drugs, 20
 Novantrone®, 3
 NSAIDs, 20
 opioids, 19
 oxybutin, 12
 phenol, 6, 31
 primidone, 7
 propranolol, 7
 reaction to, 16
 Rebif®, 3
 steroids, 18, 22
 stool softeners, 11
 tizanidine, 6
 tolteradine, 12
 Vitamin D, 22
 meditation, 8, 19
 memory, 11, 15, 34
 menopause, 21
 menstruation, 12, 21, 28
 mobility, 17, 21–22, 30, 31–32, 33
 multiple sclerosis (MS)
 age at onset, 2
 clinical course, 2
 complications, 17
 diagnosis, 2
 management strategies, summary, 3
 pathophysiology, 1–2
 prevalence, 2
 primary progressive, 2

profile of a nursing home resident with MS, vii–viii
 progressive-relapsing, 2
 relapsing-remitting, 2
 secondary progressive, 2
 symptoms, 1, 5
 unique features of nursing home residents with MS, v, 1, 5, 8, 11, 15, 19, 20, 25, 27, 30
 music therapy, 15, 31

 National Multiple Sclerosis Society (NMSS)
 objectives, v–vi, 39
 programs, 40–42
 nausea, 46
 neuralgia, trigeminal, 45
 neuropsychological issues, 15, 34–35. *See also* psychological issues
 numbness, 10, 21
 nursing homes offering specialized programming for residents with MS, 43–44
 nutrition, 8, 11, 13–14, 22–23
 nystagmus, 9

 obesity, 23
 occupational therapy, 7–8, 28, 30–31, 43
 organizations dealing with MS-related issues, 39–43, 43–44, 54–57
 osteoporosis, 18, 20–22
 overheating, 8–9, 21–22, 33

 pain, 19, 23, 45–47
 paralysis, 31
 paresthesia, 10, 19, 45
 physical therapy, 7, 30, 43
 massage, 10
 range of motion, 6, 30
 stretching, 6, 30
 pneumonia, 16
 positioning devices, 32
 pressure ulcers, 17–18. *See also* skin damage
 privacy, 27, 33
 pseudo-exacerbation of MS, 16–17, 22
 psychological issues, 24–26, 30. *See also* neuro-psychological issues
 psychosocial issues, 25

 recreation, 25
 reference books and materials, 43, 49–54
 referral programs, 40
 rehabilitation, 30–33, 43
 availability of services, 30–31
 relaxation therapy, 15

 research, 19, 26, 39–42
 respiration, 16, 24

 screening, health, general, 20–21
 seat belts, 6–7
 seizure disorder, 16
 self-help groups, 40
 sensory disturbance, 10
 complications, 10–11, 17
 sexuality, 27, 29
 skin damage, 6, 10–11, 13, 17, 17–18, 32
 sleep disturbances, 23, 26
 social interaction, 25, 30, 33
 Spanish-language reference materials, 52
 spasticity, 6–8, 17–20, 29, 31, 43, 45–47
 speech therapy, 7, 14, 16, 28, 31
 spiritual life, 15, 24, 27
 staff
 assignment, 27
 relationships with residents, 27, 29, 34
 training, v, vi, 20, 25, 29, 32, 34, 39–44
 steroid use, long-term, 18, 21–22
 stress, 7, 9
 suicide risk, 24, 26
 support groups, 40
 surgical treatments, 6, 14
 swallowing, 8, 14, 28

 teeth, 19
 thyroid, 23
 tingling, 10
 toileting, 11, 13
 tracheostomy, 16
 transfers, 6, 22, 29–31
 tremor, 7, 31, 46

 ultrasound, 19, 31
 urinary tract. *See also* bladder dysfunction
 infection, 8, 12–13, 17, 22, 45–47
 urinary frequency, 46
 urine retention, 12, 17

 vaccination. *See* immunization
 vision, 9, 18, 20, 22, 31
 vocalization, 16
 vomiting, 46

 wandering, 15
 weakness, 6, 8, 16, 22, 31
 web sites, 52–54
 weight, 23, 29
 wheelchairs, 6–7, 9–10, 17, 31–33, 35, 38

NOTES