

NURSING HOME CARE OF INDIVIDUALS WITH MULTIPLE SCLEROSIS

Guidelines and
Recommendations
for Quality Care



National Multiple Sclerosis Society
Professional Resource Center

NURSING HOME CARE OF INDIVIDUALS WITH MULTIPLE SCLEROSIS

Guidelines and Recommendations
for Quality Care

*Editors: Dorothy E. Northrop, MSW, ACSW
Debra Frankel, MS, OTR*

CONTENTS

| | |
|---|----|
| Contributors/Reviewers | 5 |
| Preface | 5 |
| Resident Profile | 7 |
| Section 1: Overview of Multiple Sclerosis | 9 |
| Section 2: Guidelines and Standards for Care | 13 |
| Clinical and Nursing Issues | 14 |
| – MS Symptom Management | 14 |
| – Complications of MS | 36 |
| – Primary Health Care Needs | 38 |
| Psychosocial Issues | 41 |
| Daily Care Issues and Related Training Needs | 44 |
| Rehabilitation Issues | 48 |
| – Availability of Rehabilitation Services | 48 |
| – Wheelchairs, Equipment, Physical Environment, and Assistive Technology | 49 |
| Neuropsychological Issues | 53 |
| Section 3: The Nursing Home Admission Process | 55 |
| Section 4: National Multiple Sclerosis Society | 59 |
| About the National MS Society | 59 |
| Training Materials and Resources | 60 |
| – National MS Society Programs | 60 |
| – Society Collaborations with Community Providers | 62 |
| – Professional Resource Center | 62 |
| – Publications for Healthcare Professionals | 62 |
| – Publications for Long-term Care Providers | 63 |
| Models of Specialized Nursing Home Care | 64 |
| Appendix A: Medications Commonly Used in MS | 69 |
| Appendix B: Recommended Resources | 73 |
| General Readings | 74 |
| Web sites | 74 |
| Organizations | 75 |
| National MS Society Publications for Lay Audiences | 79 |
| Materials Available in Spanish | 80 |

CONTRIBUTORS

National MS Society Nursing Home Task Force

Diane Afes, MA

Robert Buchanan, PhD

Nancy Cassady, MHA

Carole Downing, MSW, LCSW

Debra Frankel, MS, OTR

Lynda Hartman, RN, MS

Nancy Holland, RN, EdD

Ruta Kadonoff, MHS

Sefi Knobel, MD

Carolyn Konnert, LSW

Robert Mendoza, PhD

Dorothy Northrop, MSW

Maureen Reeder

Marva Serotkin, MPH

Elizabeth Shuster, MD

Suzanne Smeltzer, EdD, RN, FAAN

Anne-Elizabeth Straub, CSW, CFT

Cindy Walsh, RN, BSN, A-CCC

Disclaimer

The National MS Society is proud to be a source of information about MS. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription.

PREFACE

This document was developed by the National Multiple Sclerosis Society to provide guidance to clinicians and administrators of nursing home communities who are seeking to develop more effective care plans to 1) manage the unique set of clinical conditions that residents with MS present, and 2) maximize the quality of life for these residents.

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

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

As a result, nursing home staff require additional training and resources to best meet the needs of this unique population. The National MS Society 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 Society staff, health care professionals, people with MS, family members, and nursing home providers 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.

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.

PREFACE

These guidelines are 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. They are organized as follows:

- Background on the disease itself, to provide the context for the delivery of care.
- Guidelines and standards of care in the areas of clinical/nursing issues, psychosocial functioning, daily care, rehabilitation and neuropsychology.
- The nursing home placement and admission process.
- Resources and materials for additional information and training of nursing home staff and other professionals involved in providing MS care.

We also 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 living in a nursing home that serves several 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 also became diminished. Her disease progressed rapidly. She experienced trouble walking and progressed from using a cane to a wheelchair. These mobility issues and her 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 hands-on help. 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 struggled 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 made for a difficult

RESIDENT PROFILE

adjustment. 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 of 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 began to have 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. 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 to maintain her nutrition, an intervention that was very upsetting to Julie as she had always associated a feeding tube with heroic measures to extend life.

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 issues come together 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 SCLEROSIS

The next few pages provide a general description of multiple sclerosis. Nursing home residents with MS usually have the most severe form of the disease and complex clinical issues. The small percentage of people with MS who have a shortened life expectancy are more likely to reside in the nursing home setting.

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

OVERVIEW

What Causes MS?

MS is thought to be an autoimmune disease, in which the body's own defense system attacks and damages myelin, the insulating material that surrounds and protects the nerve fibers of the brain and spinal cord. There is now strong evidence that these nerve fibers can also be damaged in MS. Damage to nerve pathways and damage to their myelin sheaths causes the symptoms of MS. This damage to the myelin and the nerve fibers forms hardened "plaques", and these hardened, or "sclerotic" areas scattered throughout the brain and spinal cord gave rise to the name multiple sclerosis. When any part of the myelin sheath or nerve fiber is damaged or destroyed, nerve impulses to and from the brain are distorted or interrupted. MS is not contagious. Most individuals with MS have near-normal life expectancies.

Who Gets Multiple Sclerosis?

An estimated 400,000 Americans have multiple sclerosis. Most are diagnosed between the ages of 20 and 50, and about two thirds are women. Studies indicate that genetic factors make certain individuals more susceptible to the disease, although MS is not an inherited disease in the usual sense. Approximately 10% of people with MS have MS in their families at a higher rate than would be expected by chance. The likelihood of developing MS in the general population in the absence of its presence in a close family member is 1:1000 or 0.1%. While rare in children, some children as young as 3 or 4 have been diagnosed.

What Are the Symptoms of MS?

Symptoms of MS can include tingling, numbness, painful sensations, slurred speech, and blurred or double vision. Some people experience muscle weakness, poor balance, poor coordination, muscle tightness (spasticity), or paralysis that may be temporary or permanent. Problems with bladder, bowel, or sexual function are common, and inordinate fatigue, probably the most common symptom, is often a major source of disability. MS causes cognitive changes such as memory loss, word-finding

difficulty, and trouble concentrating in about 45-65% of people with the disease. Only in 10-15% of cases do more severe cognitive changes occur. For most people with MS, intellect is preserved. MS also causes mood swings and depression (one study indicated that the risk of suicide in the MS population may be seven times that of the general population). Symptoms vary greatly in type and severity from one person to another and may come and go unpredictably.

What are the General Patterns of MS?

MS is an unpredictable disease. Symptoms vary greatly from person to person, and may vary over time in the same person. Periods of active MS symptoms lasting more than 24 hours are called exacerbations. The disease ranges from very mild and stable to intermittent to steadily progressive. At the time of diagnosis, most people have relapsing remitting MS with attacks that last days to weeks followed by periods of partial or total remission. The periods between relapses may last months to years.

Some people with MS experience a progressive disease course with steadily worsening symptoms. The disease may worsen steadily from the onset (“primary progressive MS”) or may become progressive after a relapsing-remitting course (“secondary-progressive MS”).

Is MS Easily Diagnosed?

MS is not always easy to detect or diagnose because symptoms may come and go, and other diseases of the central nervous system have some of the same symptoms. No single neurological or laboratory test can confirm or rule out MS. Recent advances in medical imaging, particularly MRI (magnetic resonance imaging), are helping to facilitate diagnosis. A definitive diagnosis can take several months, if not years.

Can MS Be Cured?

The cause, and therefore the specific cure, of MS remains unknown, but it is the subject of intense investigation — this is an exciting era of MS research. Knowledge about MS is growing quickly. There are newer study methods, advanced imaging techniques, and many clinical trials in progress. Within the past decade unprecedented progress has been made.

Can MS Be Treated?

Yes, to a degree. At the time of the printing of this publication there are six medications approved by the Food & Drug Administration (FDA) — interferon beta 1-a (Avonex[®]), interferon beta 1-b (Betaseron[®]), glatiramer acetate (Copaxone[®]), interferon beta 1-a (Rebif[®]), mitoxantrone (Novantrone[®]) and natalizumab (Tysabri[®]) — that have been shown to reduce the frequency and severity of attacks of MS and/or delay or slow down progression of the disease.

Many medications are available to reduce some of the symptoms of MS, and many other drug therapies are being clinically

tested. Either intravenous or oral steroid administration is a method of choice for management of acute exacerbations of MS.

There are also many non-pharmacological ways to address particular MS symptoms. Physical therapy, exercise, cognitive rehabilitation, attention to diet, adequate rest, and counseling may be effective in helping people with MS maintain function, relieve discomfort, and prevent complications.

GUIDELINES AND STANDARDS FOR CARE

These guidelines, while specific to multiple sclerosis, may well apply to other nursing home residents as well. Many of the recommendations regarding psychosocial issues and quality of life are relevant to all adults. There are few studies at this time specific to the long-term care needs of individuals with advanced stages of MS. The following guidelines and standards are based upon the scientific and clinical information currently available and the practical experience of nursing home staff who have specialized in this type of care.

CLINICAL AND NURSING ISSUES

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 MS symptoms present a unique challenge to nursing and rehabilitation management. It is important that nursing home staff be aware of the unique ways these symptoms present in persons with MS, their impact on day-to-day life, and potential treatments and strategies for management of care.

While you review these symptoms remember that infections can be extremely serious, even life-threatening, in advanced MS. Fever and/or a significant increase in symptoms like fatigue, spasticity, pain, swallowing problems, or vision changes are frequently signs of infection. It is critical that whenever an infection is suspected there is immediate medical attention and prompt treatment.

MS SYMPTOM MANAGEMENT

Clinical management of the following symptoms will be addressed in this section.

- Balance
- Bladder Dysfunction
- Bowel Dysfunction
- Cognitive Changes
- Fatigue
- Heat Sensitivity
- Pain
- Respiratory Muscle Weakness
- Seizure Disorders
- Sensory Disturbances
- Spasticity
- Speech Impairment
- Swallowing Difficulties (Dysphagia)
- Tremor
- Vision Deficits
- Weakness

Balance

Balance problems cause an individual to feel unsteady and have difficulty maintaining his/her equilibrium and position in space. In MS it can cause difficulty in walking, characterized by unsteadiness and a drunken appearance (ataxia), as well as trunk instability when seated.

Attention to sitting balance is an important safety concern. Occupational and physical therapists can suggest measures for appropriate support while sitting. Supervised therapeutic exercises that challenge balance, such as use of a Swiss Ball, may be of benefit in stimulating balance centers and improving balance.

TIPS: Balance

1. The individual with MS who has balance issues requires close supervision, particularly during transfers.
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. The appropriateness of wheelchair features is best evaluated by specialists in seating and positioning, usually occupational and physical therapists.
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.
4. 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.

Bladder Dysfunction

Bladder dysfunction is very common in MS and can pose a serious threat to health. Proper management is necessary to prevent urinary tract infections and dangerous urinary retention that may damage the bladder or kidneys.

Bladder dysfunction can include frequency and/or urgency of urination, incontinence, hesitancy in starting or maintaining urine flow or, in some cases, complete inability to urinate (retention). Frequent nighttime urination (nocturia) may interfere with sleep. Assessment of bladder function by a urologist is a first step in addressing bladder issues.

Anticholinergic medications, e.g., oxybutynin (Ditropan XL®), tolterodine (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.

It is important to do periodic reassessment of bladder status. 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 be considered. This is an indwelling catheter that is placed directly into the bladder through the abdomen. There is some evidence that there are fewer infections with suprapubic catheters.

Some women with MS residing in nursing homes may still be menstruating and/or be incontinent of bladder which compounds the problem of infection with indwelling catheters.

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 limit 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 drinking 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. One such cup called a Drink-aide is available from Inglis House in Philadelphia. If the straw is within reach of the resident’s mouth, s/he can sip liquids continuously all day without needing to call for assistance.
 - 4.** Residents without catheters who are 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.
-

Bowel Dysfunction

People with MS may experience constipation as a result of inadequate fluid or bulk in the diet, decreased physical activity, medication side effects, or MS involvement. Diarrhea may occur because of leakage around fecal impaction or intestinal disease.

Interventions to address constipation include increasing fluid and fiber intake, a routinized bowel schedule, bulk formers, stool softeners, oral stimulants, glycerin suppositories, 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. Check the perianal area frequently for any signs of irritation. Double check the temperature of an 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 hyper reflexive 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.
3. Gentle massage of the abdomen may help to compensate for weak abdominal muscles and facilitate bowel motility.

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. These cognitive deficits present a significant challenge to direct care workers accustomed to working with the frail elderly population. In general, MS residents are younger, well educated and their intellect is intact. They are alert and oriented and converse with the staff as peers. Therefore it is extremely disturbing to nursing staff when residents forget that they have had care provided to them and report that they have been neglected. Residents with cognitive issues can be very convincing to nursing home ombudsmen, administrators, and family members and be accepted as accurate reporters. Staff can become particularly upset by these reports as the resident does not appear confused or demented.

A neuropsychology consult can be invaluable in defining the cognitive issue(s) and working with staff and the resident to compensate for it. Impairment of judgment, planning and organizational function may have an impact on the safety of operating wheelchairs, especially power-operated wheelchairs or scooters. An occupational therapist should be consulted to address issues of safe driving for individuals with MS who are experiencing cognitive problems.

TIPS: Cognitive Issues

- 1.** It is important for staff to have training in how to recognize and respond to people with cognitive deficits.
 - 2.** The use of compensatory strategies may be helpful to minimize the impact of cognitive deficits. Repeat information and write down important points.
 - 3.** Follow up verbal instructions with written back-up and use of visual aids.
 - 4.** Encourage the use of calendars, notebooks, and other prompts.
 - 5.** Develop consistent daily routines. Activities requiring mental effort may be better accomplished early in the day, and for a short time period and/or with frequent rest periods.
 - 6.** Sensory stimulation groups, music therapy, and relaxation therapy may be helpful.
-

Fatigue

Fatigue is one of the most common symptoms of MS. People with MS may experience normal fatigue, fatigue of depression, the fatigue of disease, and/or the fatigue of neuromuscular overuse.

MS fatigue, an overwhelming lassitude, may be treated with amantadine (formerly sold as Symmetrel®), fluoxetine (Prozac®), modafinil (Provigil®) or methylphenidate (Ritalin®). Occupational therapists can advise on energy saving techniques such as pacing of activities, planning, and balancing rest and activities. Overheating should be avoided.

Like other symptoms, fatigue can fluctuate from hour to hour or day to day. An individual with MS may be able to accomplish many tasks in the early part of the day but require assistance with the same tasks in the afternoon due to MS fatigue. Fatigue may worsen dramatically in the presence of concurrent disease, especially if fever is present, and it can be worsened by exposure to heat (including such things as a hot bath or use of an electric blanket).

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.

Heat Sensitivity

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 residents with MS. Cold drinks, cool showers and ice packs/cooling vests may also help susceptible residents. Symptoms experienced with heat should recede as the resident cools down.

TIPS: Heat Sensitivity

1. Residents need to avoid prolonged exposure to the sun during warm weather and drink plenty of cool liquids.
 2. Evaporative cooling products are made with a special polymer fabric or beads that hold water for an extended period of time. These garments are soaked in water and then placed on the body.
 3. Cold pack cooling systems are garments, usually vests, that cool through the use of special cold packs that are placed in insulated pockets.
-

Pain

Pain in MS is often related to paresthesias, spasticity, tic doloroux, and/or postural problems.

Pain is a common symptom of MS and can be exacerbated by spasticity and postural problems. Many people with MS experience tic-like pains or sharp stabbing pains without obvious cause. These may involve any body part but particularly the face, in which case the pain is called trigeminal neuralgia or tic doloroux. This is a sudden sharp stabbing pain that lasts seconds but may recur, often in bursts, frequently, throughout the day. It is very painful but is often treatable by medication. On the infrequent occasion when facial pain is intractable and excruciating, it is usually amenable to a surgical procedure.

Postural problems may cause significant back and neck pain that can be addressed with positioning strategies. Depending on the source and type of pain, various treatments may help, including antispasticity drugs, anti-convulsants, antidepressants, and opioids. Intractable pain may require more invasive methods. Alternative pain therapies such as acupuncture, ultrasound, and meditation may be effective.

Guidelines for management of chronic pain are as useful for MS residents as they are for other populations. It is, however, more common for MS residents and staff in long-term care to worry about the resident “becoming addicted” to pain killers because they are younger and have a longer life expectancy than the other residents. In general, when it comes to using narcotics for pain, long-term care nursing staff are less comfortable than their acute care counterparts. There are many excellent workshops, videos and manuals available to assist long term care facilities to address this challenging area.

TIPS: Pain

- 1.** Since different types of pain require different management, the first step is always to identify the underlying cause of the pain so that the appropriate treatment can be determined.
 - 2.** 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.
 - 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.
 - 4.** Using a rating scale on pain, from 1 to 10, can be very helpful in determining the severity of pain.
-

Respiratory Muscle Weakness

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

Weakness of the respiratory muscles due to MS may predispose a resident to pulmonary infection. While a simple cold may not pose a problem for most people, the presence of respiratory muscle weakness and inadequate deep breathing, and inability to cough, increase the risk of developing pneumonia. Individuals with weak respiratory muscles might have impaired ventilation with difficulty clearing secretions. A respiratory therapist can provide an assessment and recommend interventions, breathing exercises, and mechanical devices to stimulate breathing. Residents with tracheostomies may need suctioning or respiratory treatments. Residents should be encouraged to receive both the influenza vaccine annually and the pneumovax[®] every 7–10 years.

TIPS: Respiratory Muscle Weakness

- 1.** People with MS who have difficulty breathing often benefit from sitting upright rather than lying flat.
 - 2.** Breathing exercises during rest periods may promote relaxation.
 - 3.** Oral or nasal tracheal suctioning may at times be necessary.
-

Seizure Disorders

Seizures occur in about 5% of patients with MS.

Seizures, which are the result of abnormal electrical discharges in an injured or scarred area of the brain, are fairly uncommon among people with MS. Most seizures can be well controlled with the use of the appropriate anticonvulsant medication such as carbamazepine (Tegretol®) or diphenyl-hydantoin (Dilantin®), and continuing medical supervision.

TIPS: Seizure Disorders

1. Grand Mal seizures are often accompanied by incontinence.
2. If a seizure occurs while a person is in a wheelchair, leave the person seated if secure and safely strapped in.

Sensory Disturbances

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 incontinence.

Pressure Ulcers:

Diminished sensation accompanied by impaired mobility may result in skin breakdown. 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, risks can include 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. 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 securing the proper cushion may require that the nursing home 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.

TIPS: Sensory Disturbances

- 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 not to wear shoes or socks and/or to use a foot cradle while in bed. Light foot massage with topical anesthetics may provide temporary relief, as do ice packs at times.
 - 2.** A daily skin check by nursing staff will reduce the number of Stage 1 areas that progress to ulcers of more significance. 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. The coccyx may get shear damage from sliding in and out of bed.
 - 3.** Keep reminding staff and residents not to layer sheepskins, draw sheets and multiple incontinence pads under the resident as it 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 2-hour schedule throughout the night, try increasing the intervals to 2.5 hours for about 2 weeks — checking the skin in the 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.
-

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 (Lioresal[®]) and tizanidine (Zanaflex[®]) and occasionally diazepam (Valium[®]) and dantrolene sodium (Dantrium[®]). 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 only make things worse. It is best to stop whatever they are doing with the resident, if possible, and wait until the spasm passes before proceeding.
2. Avoid 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. It is slower and positions are held longer. It is helpful 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. Residents with significant spasticity should be transferred by an electric lift with two 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 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 seat belt serves as a positioning device to stabilize their trunk during spasms — not as a restraint.

Speech Impairment

Speech abnormalities are relatively common in MS.

Dysarthria is the most common speech problem in MS. It is characterized by slurring of speech or alteration of normal speech rhythm. It may be manifested by severe difficulty with pronunciation and articulation, making communication difficult. Some people with MS slow down speech and have word-finding difficulty, making ordinary conversation problematic. Hypophonia, a problem with volume control, may also be present. Speech problems often become more pronounced during times of stress or fatigue. Speech and language pathologists may be able to recommend assistive devices to aid communication, such as voice synthesizers, voice amplifiers, and computerized communication devices.

TIPS: Speech Impairment

1. Be patient when communicating with an individual with speech impairment, being careful not to rush the individual, complete his/her sentences, or pretend to understand when you have not.
-

Swallowing Difficulties (Dysphagia)

Abnormal swallowing is common in MS.

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 a speech therapy service 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: Swallowing Difficulties (Dysphagia)

- 1.** Encourage the resident to refrain from talking while eating.
 - 2.** Thickened iced tea and coffee resemble a coffee milkshake in texture and taste.
 - 3.** Always add the thickener just before serving the liquid. It is too thick when it stands for any length of time.
 - 4.** 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.”
 - 5.** Whenever possible, have nursing assistants who are very patient feed residents with swallowing disorders. Staff who have a hard time “slowing down” 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.
 - 6.** If there is a microwave handy, reheat food after 20 minutes to make it more palatable.
 - 7.** Teach your staff how to perform the Heimlich maneuver on a person confined to a wheelchair.
-

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 (Vistaril[®], Atarax[®]), clonazepam (Klonopin[®]), propranolol (Inderal[®]), primidone (Mysoline[®]), and isoniazid (INH) 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.

TIPS: 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 having joystick controls that require only a "light touch" can improve driving ability. Seek out wheelchair seating specialists at rehabilitation centers and/or wheelchair companies for consultation.
2. Weighted utensils or wrist weights may reduce tremor enough so that an individual can carry out more activities of daily living independently.
3. Stabilizing the elbows on the table may reduce tremor in the wrist and hands.

Vision Deficits

Optic neuritis, causing pain and acute vision loss, is common in MS as is double vision and involuntary movement of the eye (nystagmus). Cataracts may develop at a younger age in persons with MS because of corticosteroid use.

MS may affect vision in several ways. Abnormalities in activation of muscles that move the eyes can result in difficulty focusing on objects with resultant blurring or double vision. Rarely, an individual might see the world as constantly in motion or jumping (oscillopsia). Malfunction in the brain centers that control eye movement may also result in jerking movement of the eyes. This can also cause vertigo and dizziness, which can be debilitating.

Diminished vision may make it difficult for the individual to read, watch TV, go to the movies, etc., reducing many opportunities for personally satisfying activities and social interaction.

TIPS: Vision Deficits

1. Many residents with MS will require large screen TVs to view videos or TV programs.
 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 door frames will assist residents with MS to enter and exit rooms in their power wheelchairs with fewer collisions.
 5. Keeping items in the same place and not moving things around can also be helpful.
-

Weakness

Weakness results from both interrupted neurotransmission and disuse. Weakness can cause buckling of the lower limbs, clumsiness, slowness of movement, and loss of power.

Strengthening exercises may improve strength of muscles that are 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.

TIPS: Weakness

1. Physical therapy can help strengthen weakened, unconditioned muscles and improve balance and endurance. Occupational therapy offers compensatory techniques in terms of energy conservation and strengthening upper limbs.
2. It is important for staff to be trained in appropriate transfer methods. A physical or occupational therapist can demonstrate various transfer techniques, such as stand and pivot or sliding boards, and can determine which technique is most appropriate for the individual.
3. When choosing features for wheelchairs, advice should come from rehabilitation specialists and not from vendors of the products.

COMPLICATIONS OF MS

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

Osteoporosis

Long-term use of corticosteroids can result in osteoporosis, as can 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 use of medication is likely to be indicated. Particular care should be taken in transfers. Prevention of falls is very important as fractures may occur easily and heal slowly in this population.

Infections

While infections such as 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.

Insomnia

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

Sleep disturbances may be related to night time 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 with residents with MS as most cannot participate in vigorous exercise. However, exercise when 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 individuals with disabilities, it is important that the nursing home staff monitor residents' weights and provide a diet that not only meets nutritional needs but also prevents serious weight gain and obesity.

Pneumonia

For people who have underlying weakness and impaired ability to clear secretions, there is a greater predisposition to react to infections which can lead to pneumonia.

Pneumonia can occur more frequently in people with MS who are inactive and do not breathe in and out deeply. Residents with MS should discuss whether to receive the pneumonia vaccine with their physicians.

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 cause other than MS are often brushed aside as “just another manifestation of MS.” Concerns of younger residents, such as menopause, may not be adequately addressed. Some illnesses and conditions affect individuals with MS in a unique way, e.g., infections and fever. Residents with MS should adhere to the health-screening schedule that is recommended for all adults:

- Cholesterol once under age 50 and every 5 years over age 50. Patients already being treated for high cholesterol should be checked every two to six months.
- Fecal occult blood testing and colonoscopy for men and women who are over 50 or have other risk factors.
- Bone densitometry for anyone at risk for fractures or osteoporosis (particularly for those with a family history and/or reduced mobility).
- Clinical breast or testicular examination annually after age 20-25.
- Annual mammography for women after age 40-50 years.
- Vision and glaucoma exam annually over age 65.
- Hearing exam every 5 years over age 50.
- Digital rectal examination for prostate and colorectal cancers annually over age 40; PSA blood test for men over 50.
- PAP smear/gynecological exam annually (based on history and risk).
- Serum screening for dyslipidemia and thyroid abnormalities.

Health screenings such as mammography are very important but may not be routinely 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 implications for residents with MS:

Menopause

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

Menopause can cause uncomfortable symptoms such as hot flashes, vaginal dryness, sleep disturbances, and mood changes. Some residents may consider hormone replacement therapy to address these symptoms. However, since there are serious risks as well as benefits to this therapy this needs to be addressed by the person with MS and his/her physician. Thrombo-embolic risk, particularly that of deep vein thrombosis, is especially relevant in the person with MS who has mobility problems, particularly if they are overweight, and hormone replacement therapy should be avoided in such individuals. It should also be avoided in persons with a strong family history of cancer of the breast, ovarian or uterine cancers, cerebrovascular disease, and/or coronary heart disease.

Immunizations

Studies indicate that the 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 about the kinds of medical care they want to receive and 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, it is important that MS residents define their wishes clearly so that family and staff understand what measures to take or avoid regarding end of life care. Issues such as hospital vs. no hospital, intubation or not, antibiotics or not, and continued nutrition or not need to be addressed.

When quality of life seems to deteriorate for residents with very advanced MS 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).

As to cause of death for people with MS, many do die of complications related to the disease. However, many also die from issues such as cardiac and vascular disease too. There is no question that it is not always easy to identify a terminal phase of MS, even if someone has been confined to bed with significant health issues for a long time. However, if there is significant clinical compromise and respiratory weakness, UTI infections leading to sepsis, stage 4 pressure ulcers, critical nutritional impairment, or other life threatening complications, it might be time to turn to hospice for potential support.

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 on-going 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 mean that the individual with MS will undoubtedly have different needs, interests, and adjustment issues than the older resident. He/she may have young children, a spouse, and/or aging parents. Providing appropriate training for nursing and other staff in MS care, offering age-appropriate programming, and having adequate space and facilities that accommodate accessibility issues will make this difficult transition smoother and improve the quality of life for persons with MS. The following recommendations address the psychosocial needs of the younger resident with MS:

Emotional Issues

Grief is on-going, if intermittent, for a person living with MS. From the time of diagnosis and continuing throughout the course of the disease, the person experiences periods of grief — a normal reaction to significant loss.

Every change or symptom can represent a loss of self and personal identity, of autonomy and personal control, of a particular skill or ability — things that most adults cherish. Every loss of ability or control requires a change in the person’s self-image; every time the self-image undergoes a change, the person may grieve.

Anxiety is a common response to the unpredictability of MS.

From year to year, even day to day, people with MS don't know how they are going to feel or what parts of their bodies are going to be affected. Unpredictability makes people feel out of control of their bodies and their lives, and when people feel out of control, they get anxious.

Resentment is a common emotion for those who feel their life's dreams have been taken away from them.

One of the biggest challenges to people with MS is to find a satisfactory outlet for their resentment. They need to learn how to express their anger in a constructive way, focusing it on the disease rather than on those around them. They tend to feel stuck with an anger that has no outlet.

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 patients with depression if this service cannot be provided in-house.

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.

Suicide Risk

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

In National MS Society-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 is more related to a lack of connectedness with other people, and a negative self-perception of one's self, body, and one's future. 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

Family Issues

By the time people with MS come to live in a nursing home setting, most have been cared for by family members for a very long period of time.

MS is a family disease. All family members must come to terms with the disease, yet they often come to this task with different, and sometimes conflicting, coping styles. As a result of the variability of the disease, a family's rhythm and respective roles are often shifting and can require many different forms of family organization. MS can be a drain on family resources in terms of money, time, and energy. There is often ongoing tension and stress in these families as they try to balance the demands of the disease with the demands of the family. Placement of a family member with MS into a nursing home can become a tormented decision for families.

DAILY CARE ISSUES AND RELATED TRAINING NEEDS

The following recommendations reflect an approach to nursing home life and activities of daily living that resemble more of a consumer-directed model than a medical/hospital 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.

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. Residents who are younger enjoy different music, want to watch different movies, and want to eat different foods than their fellow elderly residents. They also tend to stay up later at night.

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.

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 to 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 own care.

Age-Appropriate Activities of Daily Living

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

Age-related activities of daily living may include shaving and leg waxing, or applying daily makeup. Younger women may still be menstruating and will require assistance with management of their period.

Eating

Facilitate as much independence in eating as possible since 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

Have 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 are often 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. Make sure staff are appropriately trained in transfer techniques.

Staff Relationships

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

Because staff will tend to be closer in age to residents with MS than geriatric residents they tend to identify with them to a greater degree. This may prove confusing and complicated if close friendships with residents develop. A resident may make sexual overtures to a staff member or may be the target of sexual overtures by staff. These complex relationship issues need to be anticipated when serving 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

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.

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 rehabilitation services are crucial to preventing complications and improving comfort and quality of life for these residents, insurers don’t always see it that way.

Seek individual consultations with physiatrists, occupational therapists, physical therapists, speech therapists, neuropsychologists, psychiatrists, and other appropriate staff (e.g., orthopedists, orthotists, assistive technology experts) to provide support in complex situations. Offer a customized approach to the assessment of 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, swallowing, and limitations in performing activities of daily living. Occupational therapists, physical therapists, speech therapists, 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, Transcutaneous Electrical Nerve Stimulator (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 generate 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 wheelchair needed, as well as types 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, lack of coordination, 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 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 not to 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.

Power 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 is any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional abilities of individuals with disabilities. It includes, power wheelchairs, adapted drive systems, computers, communication devices, etc. Technology can provide stimulation, counter isolation, promote self-sufficiency and control over the environment, enhance mental health, and reduce stress on staff by enabling the resident to perform tasks otherwise performed by 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. Environmental control units (ECUs) are coordinated systems for controlling many aspects of the environment through a 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. There are also many adaptations that can be used with computers to make them accessible and able to be accessed by people with a wide range of significant disabilities.

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. However, the word “intact” may be misleading. Specific cognitive deficits, such as impaired short-term memory, planning, attention, judgment, and organizational skills are common in MS. These deficits are rarely adequately described in nursing summaries and leave the impression that the resident’s general cognitive performance is unremarkable. However, 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. Specific recommendations on addressing the neuropsychological issues of nursing home residents are as follows:

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

Identify neuropsychologists in the community familiar with MS, to whom to refer residents for assessment. Some 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 residents with MS can help staff manage these behaviors more effectively.

- 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.
- 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.

Judgment, 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 and his/her family. Planning for nursing home placement is complex and laden with a variety of emotional issues. However, if families give some thought and attention to this planning process, it will be to everyone's benefit.

- **Financial Planning:** Careful evaluation of existing financial resources for nursing home care may require the services of a certified financial planner (listings are available from the National Multiple Sclerosis Society). 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 healthcare 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.
- **Family 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.

Families are likely to experience considerable guilt when placing their loved one in a nursing home setting. The many years of caregiving for a person with progressive MS can deplete a family’s emotional and physical energy.

Yet many families will feel that they are abandoning their loved one and have failed in their family's responsibilities.

Many will feel that the nursing home will never be able to care for their loved one as well as they can and this concern should be acknowledged. Nursing homes cannot possibly provide the individualized one-on-one care that most people with MS have received from their family members. On the other hand, there are things that will be gained as well. Nurses will now be available 24 hours a day and other health care professionals can be accessed much more easily. Nursing homes are busier places, with more activity and opportunity for socialization. For someone who has been basically isolated at home, perhaps even confined to bed, this environment can be more stimulating.

NATIONAL MULTIPLE SCLEROSIS SOCIETY

ABOUT THE NATIONAL MS SOCIETY

The National MS Society was founded in 1946. Sylvia Lawry, an extraordinary 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 mobilization, 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 MS Society helps each person address the challenges of living with MS through its 50-state network of chapters. The Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward.

TRAINING MATERIALS & RESOURCES

NATIONAL MS SOCIETY PROGRAMS

The National Multiple Sclerosis Society offers a wide range of programs and services to people affected by MS and engages in state and federal advocacy efforts to promote disability rights, improvements in health-care delivery, access to adequate, affordable health insurance and long-term care services, and MS-related research. Society programs and services include the following:

| | |
|--|--|
| Comprehensive information and referral services Service management and care management programs | The Society maintains a database of resources and information pertaining to all aspects of multiple sclerosis and community services available to meet the many needs generated by the disease. |
| Education | Chapters offer educational 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 | Self-help groups 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 support | The Society recognizes that informal caregivers — unpaid family, friends, and neighbors — provide the majority of long-term care services. Educational and support programs are offered by many chapters to help caregivers attend to their own emotional needs and learn how to best care and advocate for their loved one with MS. |

| | |
|--|---|
| <p>Family programs</p> | <p>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.</p> |
| <p>Advocacy</p> | <p>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.</p> |
| <p>Research</p> | <p>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.</p> |
| <p>Collaborative relationships with long-term care providers across the spectrum of care.</p> | <p>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 assisted living programs have also been developed.</p> |

To reach your National MS Society chapter call 1-800-344-4867.

SOCIETY COLLABORATIONS WITH COMMUNITY PROVIDERS

The National Multiple Sclerosis Society encourages its chapters to collaborate with local agencies and organizations to expand age-appropriate, affordable, and high quality long-term care programs for people with MS in their communities. 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 providers of such collaboration include:

- Access to expertise and experience of Society staff serving people with MS;
- In-service training of staff;
- Possibility of financial support from the chapter for discrete services or program elements;
- Marketing support;
- Assistance in identifying services and professionals in the community who can meet the complex needs of residents when they exceed the capacity of nursing home staff

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 multidisciplinary 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 can consult with experts in a variety of fields about disease management, health insurance, long term care, the development of MS specialty clinics, and more. www.nationalmssociety.org/PRC.asp

BOOKS FOR HEALTHCARE PROFESSIONALS

Multiple Sclerosis: A Focus on Rehabilitation.

Multiple Sclerosis: A Model of Psychosocial Support.

Multiple Sclerosis: The Nursing Perspective.

Multiple Sclerosis: Medication Management.

LONG-TERM CARE PROVIDER PUBLICATIONS

The Society has produced a series of guidelines documents similar to this nursing home document to help providers across the spectrum of care have a better understanding of MS and feel more comfortable serving the MS population. Most providers of long-term care services are most familiar with serving the elderly. The goal of these publications is to help them become sensitive to the needs of a younger, more disabled population and integrate this knowledge into their clinical care, daily care, rehabilitation, social work services, and activities.

Assisted Living for Individuals with Multiple Sclerosis: Guidelines & Recommendations

Guidance to administrators and staff of assisted living facilities who are seeking to develop effective service plans for residents with MS. These guidelines address such topics as resident life, clinical issues, rehabilitation, and staffing & training.

Serving Individuals with Multiple Sclerosis in Adult Day Programs: Guidelines & Recommendations

These guidelines are most helpful to those day programs that have little or no experience serving people with MS. Included in the document is basic information about MS and specific recommendations, practical tips, and best practices as they relate to intake and assessment, clinical implications, psychosocial issues, activities and wellness, rehabilitation, and staffing & physical plant.

Serving Individuals with Multiple Sclerosis in the Home: Guidelines & Recommendations for Home Care Providers and Personal Care Assistants

These guidelines serve as a practical resource to both home care agencies and privately hired personal assistants. Issues discussed include clinical issues and symptom management, assessment, primary health care needs, daily care issues, safety, emotional and family issues, rehabilitation, and wellness and community integration.

MODELS OF SPECIALIZED NURSING HOME CARE

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

California

Hillcrest Care Center

3401 Cedar Avenue
Long Beach, California 90807
562-426-4461

Hillcrest has steadily increased its number of residents with MS and now has a population of about 25. It offers several specialized programs for this younger population including yoga, meditation, cognitive fitness, assistive technology, wellness programming, internet access, and adult education. Many of the resident rooms at Hillcrest have four residents, which can be problematic for privacy. However, the residents with MS appreciate and value the innovative nature of the programming and the stress on independence and continued growth. The Southern California Chapter is very involved with the Center.

Colorado

North Star Community

3185 W. Arkansas Avenue
Denver, Colorado 80219
303-922-1169

Rowan Community

4601 E. Asbury Circle
Denver, Colorado 80222
303-757-1228

Both of these communities are managed by Pinon Management Company, a leader in the culture change movement in nursing home care. This company has a long history of serving younger adults in the nursing home setting and creates an atmosphere that is supportive to ongoing growth and independence. Both North Star and Rowan have over twenty residents with MS in each of their facilities and target their programming and activities to this younger disabled population.

Massachusetts

The Boston Home

2049 Dorchester Avenue
Boston, Massachusetts 02124
617-825-3905

In this 90+ bed nursing home in Boston, MA about 90% of the residents have MS. Services include extensive rehabilitation, an adaptive computer/assistive technology lab, a seating program, a network of medical and psychology consultants, staff training and career ladders, a volunteer program and a program of age appropriate trips and activities. Most residents with MS are between the ages of 30 and 60 years of age.

Missouri

NHC of Town and Country

13995 Clayton Road
Town and Country, Missouri 63017
636-227-5070

Town and Country responded to an RFP from the Gateway Chapter to develop a nursing home wing for people with MS in the St. Louis area. This facility now has about 15 residents with MS and has the capacity to have about 40. The chapter has been closely involved in the MS wing's development. Totally accessible, it is developing an activity program geared to a younger population who wants to be more independent. A neurologist is available to work with the MS residents, and specialized training is provided to all staff.

Nebraska

Quality Living Inc.

6409 North 70th Street
Omaha, Nebraska 68104
402-573-3700

QLI offers an extensive array of programs and rehabilitation services, particularly focused on traumatic brain injury. However, their 60 bed long-term care facility also serves other individuals with severe physical disabilities and degenerative neuromuscular disease. This includes people with MS. The Nebraska chapter works closely with QLI, and the facility often hosts its own site for the MS Walk.

New York

Beth Abraham Health Services

612 Allerton Avenue
Bronx, NY 10467
718-519-5859

Waterview Nursing Care Center

119-15 27th Avenue
Flushing, NY 11354
Tel. 718-461-5000

These two nursing homes in the NYC area serve several people with MS. Beth Abraham is a large provider with other locations in the City. Waterview is a smaller nursing home.

The Hamptons Center for Rehabilitation and Nursing

64 County Road 39, Southampton, NY 11968
631-702-1000

New, 208 bed skilled nursing facility that has developed a 40-bed specialized, residential long-term care program for adults age 18 and older with MS and related disorders. This unit is dedicated to accommodate a full range of services and activities for younger adults with disabilities.

Ohio

Beechwood Home

2140 Pogue Avenue
Cincinnati, Ohio 45208
513-321-9294

This 98-bed facility, located outside of 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. The facility primarily offers traditional nursing home care, but also has some assisted living apartments as well.

Northwestern Healthcare Center

570 North Rocky River Road
Cleveland, Ohio 44017
440-243-2122

Northwestern serves several younger adults with disabilities including over 20 residents with MS. All staff receive extensive training in MS, and clinical services include a neuro psychologist, physiatrist, counseling, and a wheelchair & mobility clinic. Northwestern has an 8-person wheelchair bus to accommodate

several wheelchair users and maintains two activity calendars — one for older residents and one for younger. Available activities include computer use, internet access, a spirituality program, restorative therapy, weekly resident meetings, and community outings.

Pennsylvania

Good Shepherd Long Term Care Facility, Inc. at Conrad W. Raker Center and Bethlehem Campus

601 St. John Street
Allentown, Pennsylvania 18103
610-776-3140

Good Shepherd has two nursing home facilities where approximately 25 residents with MS are living, as well as an MS Wellness Center that serves several people with MS from the community. Good Shepherd's primary focus is serving younger adults with disabilities. Its therapy department provides expertise in mobility, seating, and assistive technology. There is a strong emphasis on therapeutic recreation that incorporates socialization, creative expression, intellectual stimulation, physical exercise, and independent leisure activity. Oversight is provided by a strong interdisciplinary team whose goal is to maintain as much functionality and independence as possible for the longest amount of time.

Inglis House

2600 Belmont Avenue
Philadelphia, PA 19131
1-866-2-INGLIS

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. Also on campus are an adult day health program, a 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.

Virginia

The Virginia Home

1101 Hampton Street
Richmond, Virginia 23220
804-359-4093

This 130 bed facility serves several younger people with disabilities including some residents with developmental disabilities. Approximately 15% of their residents have MS. Special services include custom wheelchair fitting and technical, support, wellness programs, spirituality programs, adult education, indoor swimming pool and gymnasium, and weekly MS support group.

MEDICATIONS COMMONLY USED IN MS

This appendix provides a list of the medications commonly used in the management of MS. For each product, the table gives the generic name, the brand name, and the common usage in MS, as well as its availability in the United States and Canada. Products available without a prescription are so indicated (+).

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

| Brand Name* | Generic Name | Usage in MS |
|----------------------------------|--------------------------|-----------------------------------|
| | amantadine | Fatigue |
| | mineral oil ⁺ | Constipation |
| | papaverine | Erectile dysfunction |
| Antivert® (US) Bonamine (Can) | meclizine | Nausea; vomiting; dizziness |
| Atarax® | hydroxyzine | Paroxysmal itching |
| Avonex® | interferon beta-1a | Disease-modifying agent |
| Bactrim; Septra® | sulfamethoxazole | Urinary tract infections |
| Betaseron® | interferon beta-1b | Disease-modifying agent |
| Cialis® | tadalafil | Erectile dysfunction |
| Cipro® | ciprofloxacin | Urinary tract infections |
| Colace® | docusate ⁺ | Constipation |
| Copaxone® | glatiramer acetate | Disease-modifying agent |
| Cymbalta® | duloxetine hydrochloride | Depression, pain (neuropathic) |
| Dantrium® | dantrolene | Spasticity |
| DDAVP Nasal Spray® | desmopressin | Urinary frequency |
| DDAVP® Tablets | desmopressin | Urinary frequency |
| Decadron® | dexamethasone | Acute exacerbations |
| Deltasone | prednisone | Acute exacerbations |
| Detrol® (US) | tolterodine | Bladder dysfunction |
| Dilantin® | phenytoin | Pain (dyesthesias) |

| Brand Name* | Generic Name | Usage in MS |
|--|---|---|
| Ditropan® | oxybutynin | Bladder dysfunction |
| Ditropan XL® | oxybutynin (extended release formula) | Bladder dysfunction |
| Dulcolax® | bisacodyl ⁺ | Constipation |
| Effexor® | venlafaxine | Depression |
| Elavil® | amitriptyline | Pain (paresthesias) |
| Enablex® | darifenacin | Bladder dysfunction |
| Enemeez® Mini Enema | docusate stool softener laxative ⁺ | Constipation |
| Fleet Enema® | sodium phosphate ⁺ | Constipation |
| Flomax® | tamsulosin | Bladder dysfunction |
| H.P. Acthar Gel® | adrenocorticotrophic hormone (ACTH) | Acute exacerbations |
| Hiprex®; Mandelamine® | methenamine | Urinary tract infections (preventative) |
| Hytrin® | terazosin | Bladder dysfunction |
| Intrathecal Baclofen (ITB Therapy) | baclofen (intrathecal) | Spasticity |
| Klonopin® (US) Rivotril (Can) | clonazepam | Tremor; pain; spasticity |
| Laniazid; Nydrazid® | isoniazid | Tremor |
| Levitra® | ildenafil | Erectile dysfunction |
| Lioresal® | baclofen | Spasticity |
| Macrochantin® | nitrofurantoin | Urinary tract infections |
| Metamucil® | psyllium hydrophilic mucilloid ⁺ | Constipation |
| Minipress® | prazosin | Bladder dysfunction |
| MUSE® | alprostadil | Erectile dysfunction |
| Neurontin® | gabapentin | Pain (dysesthesias) |
| Novantrone® | mitoxantrone | Disease-modifying agent |
| Oxytrol® (Oxybutynin Transdermal System) | oxybutynin | Bladder dysfunction |

| Brand Name* | Generic Name | Usage in MS |
|---------------------------------|----------------------------------|--|
| Pamelor® (US) Aventyl® (Can) | nortriptyline | Pain (parasthesias) |
| Paxil® | paroxetine | Depression |
| Phillips' Milk of Magnesia® | magnesium hydroxide ⁺ | Constipation |
| Pro-Banthine | propantheline bromide | Bladder dysfunction |
| Prostin VR® | alprostadil | Erectile dysfunction |
| Provigil® | modafinil | Fatigue |
| Prozac® | fluoxetine | Depression; fatigue |
| Pyridium® | phenazopyridine | Urinary tract infections (symptom relief) |
| Rebif® | interferon beta-1a | Disease-modifying agent |
| Sanctura® | tropium chloride | Bladder dysfunction |
| Sani-Supp Suppository® (US) | glycerin ⁺ | Constipation |
| Solu-Medrol® | methylprednisolone | Acute exacerbations |
| Tegretol® | carbamazepine | Pain (trigeminal neuralgia) |
| Tofranil® | imipramine | Bladder dysfunction; Pain |
| Tysabri® | natalizumab | Disease-modifying agent |
| Valium® | diazepam | Spasticity (muscle spasms) |
| Vesicare® (US) | solifenacin succinate | Bladder dysfunction |
| Viagra® | sildenafil | Erectile dysfunction |
| Wellbutrin® | bupropion | Depression |
| Zanaflex® | tizanidine | Spasticity |
| Zoloft® | sertraline | Depression |

⁺Available without a prescription.

* Available in both US and Canada unless otherwise noted.

RECOMMENDED RESOURCES

GENERAL READINGS

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

Bowling A. *Alternative Medicine and Multiple Sclerosis* (2nd ed.) 2007.

Coyle P, Halper J. *Living with Progressive Multiple Sclerosis* (2nd ed.) 2008.

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* (3rd ed.) 2007 (Also in Spanish)

Kalb R. *Multiple Sclerosis: A Guide for Families* (3rd ed.) 2005

Kalb R. *Multiple Sclerosis: The Questions You Have—The Answers You Need* (4th ed.). 2008

Perkins L, Perkins S. *Multiple Sclerosis: Your Legal Rights* (3rd ed.) 2008

Rumrill PD (ed.). *Employment Issues and Multiple Sclerosis* (2nd ed.) 2008

Schapiro RT. *Managing the Symptoms of Multiple Sclerosis* (5th ed.). 2007

WEB SITES

ABLEDATA

Information on Assistive Technology

www.abledata.com

Consortium of Multiple Sclerosis Centers

www.mscares.org

International Journal of MS Care

www.mscares.com

Medicare Information

www.medicare.gov

Multiple Sclerosis International Federation

www.msif.org

The Multiple Sclerosis Society of Canada

www.mssociety.ca

National Family Caregivers Association

www.nfcacares.org

National Institute of Neurological Disorders and Stroke

www.ninds.nih.gov

National Multiple Sclerosis Society

www.nationalMSSociety.org

National Organization for Rare Disorders (NORD)

www.rarediseases.org

ORGANIZATIONS

Consortium of Multiple Sclerosis Centers (CMSC)

359 Main Street, Hackensack, NJ 07601

Tel: 201-487-1050; Web site: www.mscares.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; Web site: www.va.gov

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.

Health Resource Center for Women with Disabilities

Rehabilitation Institute of Chicago, 345 East Superior Street,
Chicago, IL 60611

Tel: 800-354-7342; Web site: 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: info@iomsn.org;

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 Association of America

766 Haddonfield Rd, Cherry Hill, NJ, 08002

Tel: 800-532-7667; Web site: www.msassociation.org

A national non-profit organization dedicated to enriching the quality of life for everyone affected by MS. MSAA provides ongoing support and direct services to individuals with MS and their family members.

Multiple Sclerosis Foundation

6350 North Andrews Avenue, Fort Lauderdale, Florida, 33309-2130

Tel: 800-225-6495; Web site: www.msfocus.org

The Multiple Sclerosis Foundation offers an array of free services including national toll-free support, educational programs, home care, support groups, assistive technology, and publications to improve the quality of life for those affected by MS.

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; Web site: www.mssociety.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; Web site: 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; Web site: 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

733 Third Avenue, New York, NY 10017

Tel: 800-344-4867; Web site: www.nationalMSSociety.org

The National MS Society is a nonprofit organization that supports a range of efforts to prevent, cure, and treat 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 local resources by calling 1-800-344-4867 for up-to-date information and referrals.
- Website with updated information and educational programs, for lay audiences and professionals, related to treatments, research, and programs. www.nationalMSSociety.org, for the national site. Additionally, many chapters maintain websites for their service areas.
- Professional Resource Center (Tel: 1-866-MS-TREAT; E-mail: 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
- 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.
- MS Learn Online, an online education series for people with MS and their families, available on the National MS Society website.
- Printed materials available on a variety of topics.
- Educational programs on various topics throughout the year, provided at chapters around the country.
- Annual national teleconference at over 500 sites throughout the United States; call 1-800-344-4867 for the location nearest you.
- Wellness programs

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; Web site: 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; Web site: 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.

United Spinal Association

75-20 Astoria Boulevard, Jackson Heights, NY 11370

Tel: 718-803-3782; Web site: www.unitedspinal.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.

Well Spouse Foundation

30 East 40th St., PH, New York, NY 10016

Tel: 212-685-8815; 800-838-0879; E-mail: info@wellspouse.org;

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.

NATIONAL MS SOCIETY PUBLICATIONS FOR LAY AUDIENCES

Call 1-800-344-4867 or visit www.nationalMSSociety.org to find these publications.

| | |
|--|------------|
| Living with MS | ES 0087 |
| What Everyone Should Know About Multiple Sclerosis (not available on Web site) | ER 0100 |
| Research Directions in Multiple Sclerosis | ES 6017 |
| ADA and People with MS | ES 6021 |
| The Win-Win Approach to Reasonable Accommodations: Enhancing Productivity on Your Job | ES 6025 |
| Managing MS Through Rehabilitation | ES 6022 |
| Controlling Spasticity in MS | ES 6037 |
| Stretching for People with MS | ES 6041 |
| Stretching with a Helper for People with MS | ES 6042 |
| 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 | ES 6035 |
| Solving Cognitive Problems | ES 6029 |
| Controlling Bladder Problems in Multiple Sclerosis | ES 0039 |
| Bowel Problems: The Basic Facts | Fact Sheet |

| | |
|--|---------|
| PLAINTALK: A Booklet About MS for Families | ES 0055 |
| Someone You Know Has MS: A Book for Families | ES 0045 |
| When a Parent Has MS: A Teenager's Guide | ES 6024 |
| A Guide for Caregivers | ES 6010 |
| Clear Thinking About Alternative Therapies | ES 6038 |

MATERIALS AVAILABLE IN SPANISH

Controlando 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?
 La Fatiga: Lo Que Usted Debe Saber
 Diagnóstico: Hechos Básicos sobre Esclerosis Múltiple
 Cuidando de una persona con Esclerosis Múltiple—Una Guía para Cuidadores
 Ejercicios Prácticos de Estiramiento para las Personas con Esclerosis Múltiple
 Ejercicios Prácticos de Estiramiento con un Ayudante para las Personas con Esclerosis Múltiple
 Hoja bilingüe de información sobre la esclerosis múltiple

Antivert® is a registered trademark of Pfizer Pharmaceuticals, Inc.
 Atarax® is a registered trademark of Majedo, Corp
 Aventyl® is a registered trademark of Eli Lilly and Co.
 Avonex® is a registered trademark of Eli Lilly and Co.
 Betaseron® is a registered trademark of Bayer Schering Pharma Aktiengesellschaft
 Botox® is a registered trademark of Allergan, Inc.
 Cialis® is a registered trademark of Lilly ICOS
 Cipro® is a registered trademark of Bayer Aktiengesellschaft
 Colace® is a registered trademark of Roberts Laboratories
 Copaxone® is a registered trademark of Teva Pharmaceutical Industries Ltd.
 Cymbalta® is a registered trademark of Eli Lilly and Co.
 Dantrium® is a registered trademark of Procter & Gamble
 DDAVP Nasal Spray® is a registered trademark of Aventis Pharmaceuticals, Inc.
 DDAVP® is a registered trademark of Aventis Pharmaceuticals, Inc.
 Decadron® is a registered trademark of Merck & Co.
 Detrol® is a registered trademark of Pfizer
 Dilantin® is a registered trademark of Warner-Lambert Co.

Ditropan XL® is a registered trademark of Alza Corp.
Ditropan® is a registered trademark of Alza Corp.
Dulcolax® is a registered trademark of Boehringer Ingelheim Int'l
Effexor® is a registered trademark of Wyeth Corp.
Elavil® is a registered trademark of Zeneca, Inc.
Enablex® is a registered trademark of Novartis International Pharmaceutical Ltd.
Enemeez® Mini Enema is a registered trademark of Arizona Contract Specialist Inc.
Fleet Enema® is a registered trademark of C.B. Fleet Co., Inc.
Flomax® is a registered trademark of Refractory Technology, Inc.
H.P. Acthar Gel® is a registered trademark of Questcor Pharmaceuticals, Inc.
Hiprex® is a registered trademark of Aventis, Inc.
Hytrin® is a registered trademark of Abbott Laboratories
Inderal® is a registered trademark of Wyeth Corp
Klonopin® is a registered trademark of Hoffman-LaRoche Inc., Corp.
Levitra® is a registered trademark of Bayer Aktiengesellschaft
Lioresal® is a registered trademark of Ciba Geigy Corp.
Macrochantin® is a registered trademark of Procter & Gamble Pharmaceuticals
Mandelamine® is a registered trademark of Warner Chilcott Co.
Metamucil® is a registered trademark of Procter & Gamble Co.
Minipress® is a registered trademark of Pfizer Pharmaceuticals, Inc.
MUSE® is a registered trademark of Vivus, Inc.
Mysoline® is a registered trademark of Valeant Pharmaceuticals
Neurontin® is a registered trademark of Warner-Lambert Co.
Novantrone® is a registered trademark of Immunex Corp
Nydravid® is a registered trademark of E.R. Squibb & Sons, LLC
Oxytrol® is a registered trademark of Watson Pharma, Inc.
Pamelor® is a registered trademark of Mallinckodt, Inc.
Paxil® is a registered trademark of SmithKline Beecham Corp.
Phillips' Milk of Magnesia® is a registered trademark of Bayer HealthCare
Pneumovax® is a registered trademark of Merck & Co.
Prostin VR® is a registered trademark of Pharmacia & Upjohn
Provigil® is a registered trademark of Cephalon, Inc.
Prozac® is a registered trademark of Eli Lilly and Co.
Pyridium® is a registered trademark of Warner Chilcott Co.
Rebif® is a registered trademark of Ares Trading S.A.
Ritalin® is a registered trademark of Novartis Corp.
Sanctura® is a registered trademark of Allergan, Inc.
Sani-Supp Suppository® is a registered trademark of G&W Laboratories, Inc.
Septra® is a registered trademark of Monarch Pharmaceuticals
Solu-Medrol® is a registered trademark of Pharmacia & Upjohn Co.
Symmetrel® is a registered trademark of Endo Pharmaceuticals
Tegretol® is a registered trademark of Novartis Corp.
Tofranil® is a registered trademark of Mallinckrodt
Tysabri® is a registered trademark of Elan Pharmaceuticals, Inc.
Valium® is a registered trademark of Roche Products, Inc.
Vesicare® is a registered trademark of Astellas Pharma
Viagra® is a registered trademark of Pfizer, Inc.
Vistaril® is a registered trademark of Pfizer, Inc.
Wellbutrin® is a registered trademark of SmithKline Corp
Zanaflex® is a registered trademark of Elan Pharmaceuticals Inc.
Zolof® is a registered trademark of Pfizer, Inc.

**MOVING TOGETHER
TOWARD A WORLD
FREE OF MULTIPLE
SCLEROSIS.**



**National
Multiple Sclerosis
Society**

733 Third Avenue
New York, NY 10017-3288

Professional Resource Center
R_X