National Multiple Sclerosis Society

Serving Individuals with Multiple Sclerosis in Adult Day Programs:

Guidelines & Recommendations

National Multiple Sclerosis Society
Clinical Programs Department
Professional Resource Center

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New York, NY 10017-3288

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

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DISCLAIMER

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

SECTION
1

Introduction

The National Multiple Sclerosis Society (NMSS) developed this document to provide guidance to staff and administrators of adult day programs who are seeking to better meet the needs of their participants with MS.

Multiple sclerosis is a complex, chronic disorder of the central nervous system that often generates needs for a range of long-term care services, including rehabilitation services, home care, adult day care, assisted living, and nursing home care. Individuals with MS often present a unique cluster of needs and when program staff are sensitive to these needs and knowledgeable about MS care, the experience can be a successful one for all involved.

As compared to the more 'traditional' elderly adult day program participant, those with MS are more likely to:

- be younger
- be more mentally alert
- be more physically dependent
- remain in the program longer

As a result, your program staff may require additional training and resources to best address the care needs of this population.

The NMSS is considered to be a leader in the initiation, support, and promotion of quality and age-appropriate care options for people with MS. Consistent with this responsibility, the Society recently convened an expert panel of NMSS home office and chapter staff, MS clinical specialists, adult day program directors and clinicians (from both generic and MS specific facilities), and experts in the fields of mental health, social services, therapeutic activities and rehabilitation, to identify the key components of quality adult day programming for people with MS. This task force contributed their knowledge and clinical expertise to the preparation of this document through a series of meetings and research on best practices.

This document is designed to be a practical resource for all adult day programs serving people with MS, from those serving only one or two MS participants to those providing specialized care to this population. It should be useful to program directors, nursing staff, rehabilitation professionals, activities staff, social workers, mental health professionals, and others involved in adult day programs.

It is organized as follows:

- Background on multiple sclerosis, to provide the context for the delivery of care
- Intake and assessment of participants with MS
- Unique clinical issues that are characteristic of the disease and have implications for adult day programs
- The complex psychosocial needs that can be generated by MS
- Appropriate therapeutic activities
- Rehabilitation needs
- Staffing, training and physical plant issues

We recognize that adult day programs are different in terms of physical plant, staffing, and programming. Some offer primarily social programming, while others have a significant medical component. Some may offer on-going rehabilitation services, while others may only contract for these services on an individual referral basis. Whatever the nature of your particular program, we hope that this publication will provide useful and practical information that will help to enhance your programming for people with multiple sclerosis.

Please feel free to contact the National Multiple Sclerosis Society at 1-800-FIGHT-MS for more information about this document and multiple sclerosis.

WHAT IS MULTIPLE SCLEROSIS?

MS is thought to be an autoimmune disease that affects the central nervous system (CNS). The CNS consists of the brain, spinal cord, and the optic nerves. Surrounding and protecting the nerve fibers of the CNS is a fatty tissue called myelin, which helps nerve fibers conduct electrical impulses.

In MS, myelin is lost in ***multiple*** areas, leaving scar tissue called ***sclerosis***. These damaged areas are also known as plaques or lesions. Sometimes the nerve fiber itself is damaged or broken.

Myelin not only protects nerve fibers, but also makes their job possible. When myelin or the nerve fiber is destroyed or damaged, the ability of the nerves to conduct electrical impulses to and from the brain is disrupted, and this produces the various symptoms of MS.

People with MS can expect one of four clinical courses of disease, each of which might be mild, moderate, or severe.

- ***Relapsing-Remitting:*** People with this type of MS experience clearly defined flare-ups (also called relapses, attacks, or exacerbations). These are episodes of acute worsening of neurologic function. They are followed by partial or complete recovery periods (remissions) free of disease progression. This is the most common form of MS at time of initial diagnosis.
- ***Secondary-Progressive:*** People with this type of MS experience an initial period of relapsing-remitting disease followed by a steadily worsening disease course, with or without occasional flare-ups. About 50% of people with relapsing-remitting MS develop this form of the disease within 10 years of their initial diagnosis.
- ***Primary-Progressive:*** People with this type of MS experience a slow but nearly continuous worsening of their disease from the onset, with no distinct relapses or remissions. However, there can be variations in rates of progression over time, occasional plateaus, and temporary minor improvements.
- ***Progressive-Relapsing:*** People with this type of MS experience a steadily worsening disease from the onset but also have clear acute attacks as well.

WHAT CAUSES MS?

While the exact cause of MS is unknown, most researchers believe that the damage to myelin results from an abnormal response by the body's immune system called an autoimmune response. Normally, the immune system defends the body against foreign invaders such as viruses or bacteria. In autoimmune diseases, the body attacks its own tissue. It is believed that MS is an autoimmune disease and that it is the myelin that the body attacks. Scientists do not yet know what triggers the immune system to do this. Most agree that several factors are involved, including: genetics, gender, and environmental triggers (e.g., a virus or toxic environmental material).

It is important to note that MS is not contagious and is not usually fatal. MS is not inherited, although a genetic predisposition is probable and being studied

WHO GETS MS?

Anyone may develop MS, but there are some patterns.

- Most people with MS are diagnosed between the ages of 20 and 50.
- Two to three times as many women as men have MS.
- Studies indicate that genetic factors make certain individuals more susceptible than others, but there is no evidence that MS is directly inherited.

- MS occurs more commonly among people with northern European ancestry, but people of African, Asian, and Hispanic backgrounds are not immune. (In fact, in some locations adult day programs will reflect the local community and will have a majority of participants who are not of northern European ancestry.)

Approximately 400,000 Americans have MS, and every week about 200 people are diagnosed. Worldwide, MS may affect 2.5 million individuals.

WHAT ARE THE SYMPTOMS OF MS?

Symptoms of MS are unpredictable and vary from person to person and from time to time in the same person. For example, one person may experience abnormal fatigue, while another might have severe vision problems. A person with MS could have loss of balance and muscle coordination making walking difficult; another person with MS could have slurred speech, tremors, stiffness, and bladder problems. While some symptoms will come and go over the course of the disease, others may be more lasting. Symptoms seen in individuals in an adult day program may be more severe or disabling.

Symptoms include: mobility problems (weakness, incoordination, problems with balance, muscle stiffness, tremors), fatigue, bladder and bowel problems (incontinence, urgency, frequency, constipation), changes in cognition (reduced short-term memory, attention and problem solving), abnormal sensations (numbness, tingling, painful sensations), vision problems, speech and swallowing problems and sexual dysfunction.

HOW IS MS DIAGNOSED?

At this time, no single test is available to identify or rule out MS. Several tests and procedures are needed. These are likely to include:

- ***Complete Medical History:*** Healthcare providers need an overall view of the individual's health picture, including symptoms and when they began.
- ***Nervous System Functioning:*** Testing of reflexes, balance, coordination, and vision—as well as checking for areas of numbness.
- ***Diagnostic Tests*** such as:
  - MRI scan, which gives a detailed view of the brain.
  - Evoked potential tests, which measure how quickly and accurately a person's nervous system responds to certain stimulation.
  - Spinal tap, which checks spinal fluid for signs of the disease.

Two basic signs are required to confirm MS: (1) signs of disease in different parts of the nervous system ***and*** *(2) signs of at least two separate flare-ups (also called relapses or exacerbations) of the disease.*

HOW IS MS TREATED?

Management of MS involves the following:

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

PARTICIPANT PROFILE

Note: *Julie is not a factual person, but a composite of several persons with MS. This profile illustrates some of the wide range of issues an individual with MS may present. Depending on the level of care your program provides, you may or may not be able to meet the needs of this hypothetical participant.*

> **"MS leaves you by yourself. You feel alone. It becomes the focus of your life. It comes to live with you. You have to come to live with it."**

Julie is a 49-year-old, married, white female who was admitted to the program four years ago. She is a college graduate with an advanced degree in education and had a career working with learning disabled children. Her family consists of her husband, two teenage sons who are away at college, and elderly parents. Julie had always been a very independent person and took great satisfaction in being able to raise her family, maintain a successful career, and run her own life.

In her late twenties, when her sons were in elementary school, she had an episode of blurred and diminished vision and went 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 had previously been very healthy. She continued teaching, but after about ten years other symptoms appeared. She was embarrassed about her unsteady gait and worried that people might think she had been drinking. She began to have trouble remembering appointments and processing information. Her reasoning and problem solving were also diminished. Her disease progressed rapidly. She experienced trouble walking and progressed from using a cane to using a wheelchair if she had to travel any distance. These mobility issues and the

cognitive decline ultimately caused her to resign her teaching position. While Julie was coping with these losses, her teenaged sons also struggled with these changes in their family. It was a stressful situation for everyone.

Julie began receiving visiting nurse services several days each week. By age 45, she was experiencing frequent falls at home. At that time her sons were already away at college. Her husband worked full time and became increasingly uncomfortable with his wife being home alone all day (with the exception of a couple of hours of home health care). He was also finding that at the end of his long workday, he had little patience or energy to care for Julie and he was afraid that he was becoming verbally abusive to her. Her parents were able to provide some assistance, but they were elderly, with health problems of their own.

Julie and her husband decided to try an adult day program so that Julie could socialize with other people during the day, be in a safe, supervised environment, receive help with her injectable medication and self care, and have access to rehabilitation services. Even though it was a joint decision, Julie felt angry that she could no longer be alone at home. She was frightened that this was the first step on the road to greater dependence. The first several months were difficult as she struggled with this new chapter in her life. Furthermore, many of the other participants were elderly and she initially didn't think she had much in common with them.

After a while, Julie was unable to mobilize her own manual wheelchair. The program referred her to a seating and positioning clinic where a team of occupational and physical therapists provided a comprehensive assessment, and enabled her to obtain the most appropriate power wheelchair for her current and future needs. She was now able to go outdoors on her own and relax in a private spot in the center's garden. She was able to participate in the program's outings to museums and shopping without getting exhausted. And on weekends, she and her husband could go out to dinner or visit friends more easily. Her husband also found that her evening care was reduced because the nurse at the program gave Julie the injections for her disease-modifying therapy on the days that she was in the program. Julie was more cheerful and relaxed.

Julie made a few friends at the program. She met an elderly man who had been a school superintendent and they enjoyed talking together about education issues. The day program staff arranged for her to tutor another participant who was a new immigrant and just learning English and that made her feel that she could still use her teaching skills and that she had something to give others.

The program staff are concerned that her transfers sometimes require the help of two people but they are committed to having her remain in the program. She comes 3 days per week and has been in the program for four years. She seems to benefit from the socialization, the group exercise sessions, and the activities program. She is also monitored medically, and receives her injections regularly. Her husband finds that the peace of mind and reduced responsibility for her daily care has significantly helped their relationship.

SECTION
2

Intake and Assessment

INTAKE

The intake process most often begins with a telephone inquiry by the individual with MS or his/her caregiver. This brief telephone interview offers staff the opportunity to:

- Describe the program and clarify the services offered.
- Begin to gain an understanding of the needs and expectations of the potential participant.
- Assess interest in the program on the part of the individual and his/her family members/caregivers.

Most centers offer potential participants an opportunity to visit the center and/or participate in a 'trial day'. Exposing the potential participant to the activities of the program, the environment, and the other participants is valuable in determining whether there is an appropriate match between the individual's needs and interests and the program's offerings.

Each state and each program may use different criteria to determine if an individual is appropriate for admission to the program. Some require that the individual be able to transfer independently or be fully continent. Others may allow Hoyer lift transfers and assistance with toileting. Some programs may be equipped to help a participant change and shower if they are incontinent; others do not have the facilities to do this.

Be sure the participant fully understands your admission and discharge criteria. Provide information orally and in writing. Explain these criteria to a family member as well. Most importantly, the program must answer the following questions affirmatively before admitting any potential participant.

- "Can we meet the needs of this individual?"
- "Will this individual benefit from the program we offer?"
- "Is an adult day program the most appropriate setting for this individual, or do they require referral to other support services?"

Affordability is often a concern for potential participants. Participants who are Medicaid recipients may be eligible for adult day coverage. Home and Community-Based Waiver programs are now in place in many states and may cover adult day services. (Look for funding programs with names such as 'community integration" and "community options" in the title.) Medicare may also cover some services (such as PT or OT) in the adult day setting. State and county funding options should be explored as each has its own unique funding streams. Private and community agencies might also be a resource for funding.

Once admission to the program is agreed upon, the individual and the center staff should enter into a contract so that expectations are clear. Discharge criteria should be addressed at this time as well, as circumstances under which the participant might be asked to leave the program must be clearly understood. Providing the new participant with a copy of the agreement may also prove helpful.

Facilitating the Admission Process

> **"I like having older and younger people together. The older people give us wisdom; we give them youth."**

MS makes severe emotional demands on those living with the disease. Individuals and families are confronted with many functional and physical losses, major changes in family and social roles, and loss of control over many life decisions. The individual in adult day may be resistant to joining a program and participating at first, and may experience problems in adjusting. Sensitivity and understanding of the emotional and social needs generated by MS can help program staff facilitate adjustment for new participants. Assigning both a staff member and veteran participant as a 'buddy' to the new person may help to give needed initial support and orientation.

Highlighting the many emotional benefits of participating in adult day care—opportunities to meet others, make friends, develop new interests, have a life outside of the home and something to talk about at the end of the day, can help potential and new participants feel better about this change in their lives with MS. It is also important to address any concern that an applicant might have that attendance at a day program could negatively impact their access to home care services, or their relationship with a particular home health aide.

Adult day services can bring a great relief to family caregivers. These services may enable family members to continue working and provide the respite necessary for emotional health. Often adult day services provide the support needed to enable the individual to remain in their own home and delay out-of-home placement.

ASSESSMENT

Assessment at admission to the program should ideally involve an evaluation of the following areas:

- Health status (current MS symptoms, other medical needs, medications)
- Emotional health (evidence of depression, emotional lability, behavioral issues)
- Cognitive status (symptoms of cognitive dysfunction, ability to participate in the program, self-awareness)
- Functional status (mobility, transfers, self-care, toileting, bathing, feeding and swallowing issues, fatigue, use of assistive technology, fluctuations in ability over course of day, speech and hearing, vision)
- Psychosocial status (including family roles, living situation, employment and education history, sexuality, status or other support services such as hours of home care)
- Wellness/Fitness status (including tobacco and alcohol consumption, health maintenance behaviors, exercise history, nutrition, stress management, spiritual outlook and resources)
- Leisure status (hobbies, interests)
- Safety (falls, judgment)
- Caregiver concerns and priorities
- Participant concerns and priorities
- Source of funding for day program participation

Depending on your program's resources, staffing and mission, the extent of your initial assessment will vary. Some programs obtain a brief summary of medical status and conduct an informal interview to gather basic information regarding needs, interests, and function. Other programs may conduct more extensive, formal assessments using standardized assessment tools.

Below are suggested questions that can help you determine the status, needs and interests of the new participant with MS, as well as recommendations of standardized assessment tools that are available to more formally evaluate a particular functional area. More information about these tools and how to obtain them is included in the appendices of this document.

Assessment of the New Participant		
Domain	**Key Questions**	**Assessment Tools**
Physical Health Status	• What are your current MS symptoms? (Include bladder and bowel dysfunction.) • What are your current medications? (It is helpful to have the participant actually show you the prescription bottles.) • Do you take an injectable medication for your MS? • Do you have any allergies? • Do you experience other medical problems? • Have you had recent hospitalizations, trips to the ER, or other medical interventions? • What is your overall health status aside from MS?	• Standard Medical History
Psychosocial Status	• Are you depressed, anxious? • What are your reasons for coming to the program? • What is your marital status? • What is your level of education? • What is your employment history? i.e., What type of work did you do? • Who are the members of your family? • What are your family's concerns about your MS? • With whom do you live? • Do you use tobacco/cigarettes/recreational drugs? • How will you be transported to the program? • What are the biggest challenges you face in living with MS day-to-day?	• Multiple Sclerosis Quality of Life Inventory (MSQLI) • Standard History

Domain	Key Questions	Assessment Tools
Functional Status	• What mobility devices do you use? • Does your ability tend to fluctuate throughout the day? • What kind of assistance do you need with feeding, toileting, self-care, transfers, ambulation? • What is your experience with MS fatigue? • Do you have difficulty with memory, organizing your thoughts, paying attention or other cognitive processes? • Do you experience falls? • Do you have difficulty with speech or communicating with others? • Do you have difficulty swallowing?	• Minimal Assessment of Cognitive Function in MS (MACFIMS) • Multiple Sclerosis Functional Composite (MSFC) • Functional Independence Measure (FIM) • Barthel Index • MSQLI • Berg Balance Test
Leisure Interests	• What were your hobbies and leisure interests prior to MS? • What are your hobbies and leisure interests now? • What new hobbies might you like to try at the day program? • Would you like to attend school or take courses?	• Idyll Arbor Leisure Battery • Idyll Arbor Leisure Inventory

SAMPLE INTAKE/ASSESSMENT APPLICATION

In Appendix A, on pages 53–63, is an intake/assessment application form used by the Marilyn Hilton MS Achievement Center, a specialized day program for people with MS. This model assessment tool can be adapted for your program's needs. It contains questions specifically geared to the participant with MS and will provide you with practical information that will be very helpful in the development of a care plan.

SECTION
3

Clinical Issues and Symptom Implications

CLINICAL ISSUES

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

Information about intervention and management is provided here to alert staff as to how these symptoms may be addressed and to describe the range of clinical experiences that individuals with MS have. It is not assumed that these interventions will necessarily be provided by the adult day program staff.

MS SYMPTOM MANAGEMENT

The following symptoms of MS generate a wide variety of care needs. While not all of these symptoms will be present in any one individual, the nature of the disease is such that multiple symptoms will be present. Access to appropriate health services and management of these symptoms are critical to avoiding clinical complications and preventing avoidable physical decline.

Symptoms are listed in alphabetical order, not in order of prevalence in persons with MS.

Balance Problems

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

TIPS: Balance Problems

1. The participant may require close supervision, especially during transfers.
2. Handrails and grab bars strategically placed may provide safe and independent mobility. Canes or walkers can help prevent falls for ambulatory participants.
3. Side trunk supports and seat belts (as positioning devices, not as restraints) are often recommended for seating balance, as are wheelchairs with a "tilt" feature if balance issues are severe. The appropriateness of these wheelchair features are best evaluated by specialists in seating and positioning, which include occupational and physical therapists.
4. Supervised therapeutic exercises that challenge balance may be helpful in stimulating balance centers and improving balance, but compensatory measures, such as use of a cane, may be necessary. These measures are best determined by a physical and occupational therapy evaluation.

Bladder Dysfunction

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

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

(more information about bladder dysfunction appears on the next page)

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

TIPS: Bladder Dysfunction

1. Some individuals report that cranberry extract in gel cap or tablet form or cranberry juice is helpful for prevention of recurrent urinary tract infection.
2. Individuals who suffer from urgency and/or bladder spasms should avoid caffeinated and carbonated beverages.
3. Individuals should NOT necessarily sip fluids all day to remain hydrated. They should try to drink most of their fluids with their meals and go to the toilet 60–90 minutes later. A practical intake volume is approximately six 8-ounce glasses of fluid per day. This is based on anecdotal experience.
4. Bathroom facilities placed conveniently near activity areas will make it easier for those dealing with bladder issues.
5. Individuals who leak urine should wear appropriate protection. Suggesting the use of pads or protective garments needs to be approached with sensitivity to the individual's possible sense of humiliation and loss of dignity. This would best be done by a trusted staff member, ensuring confidentiality and privacy. If leaking urine becomes excessive, a urologic assessment may be indicated.
6. Skin irritation or breakdown may ensue if the individual is frequently wet. Instruct the participant in how to examine and protect the skin.
7. There are many types of leg bags and even a "belly bag" which can be worn by individuals with indwelling catheters. These are not visible to others and thus will not interfere as much with social activities.
8. Some individuals with MS may elect surgical procedures to manage continence.
9. The National Association for Continence can be a helpful resource of information on bladder issues. Contact information is listed in Appendix C.

Bowel Dysfunction

People with MS may experience constipation because of inadequate fluid or bulk in the diet, decreased physical activity, medications, and/or from MS involvement that may slow the bowel or weaken abdominal muscles. Interventions that the participant may be doing at home might include increasing fluid and fiber intake, a routine bowel schedule, bulk formers, stool softeners, oral stimulants, laxatives, and mechanical stimulation. Frequent use of enemas is not recommended but may be necessary for optimal scheduling of activities and may also be the preference of the person with MS.

Individuals may have decreased rectal sensation, causing the individual to feel uncertainty as to complete elimination. Incomplete elimination may lead to fecal impaction. Incontinence of stool may occur in some individuals. This often leads to social isolation if the participant becomes afraid of public incontinence.

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

TIP: Bowel Dysfunction

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

Cognitive Changes

Persons with MS may experience a range of cognitive problems and when present, these deficits may range from quite mild to severe. Rarely, however, will an individual with MS present with global dementia or disorientation. Specific cognitive deficits, such as impaired short-term memory, ability to multi-task, planning, attention, word finding, judgment, and organizational skills, are found in MS. Additionally, MS may affect the ability to process information in a timely manner and readily adapt to changing situations. These cognitive impairments may cause a person with MS to become dependent on caregivers, even if his/her physical disability is minimal. These persons may isolate themselves because they can no longer 'keep up'. In general, intelligence in persons with MS who have cognitive changes remains intact.

TIPS: Cognitive Changes

1. Provide training to nursing and direct care staff in recognizing and responding to people with cognitive deficits. Sensitivity and awareness of the cognitive and emotional issues that may influence the behavior of the participant can help staff manage behaviors more effectively.
2. Include training to staff in differentiating the cognitive deficits associated with MS from those associated with Alzheimer's disease and related dementias.
3. Recognize that a participant's ability to self-report may be impaired, but their awareness of cognitive impairment will be significantly greater than older clients with dementia. Many individuals with MS who experience cognitive impairments are very aware of their difficulties, which can increase their frustration and decrease their willingness to try new things.
4. Develop consistent daily routines.
5. Provide stimulating and interesting activities to help participants with cognitive deficits use intact skills.
6. Activities requiring mental effort may be better accomplished early in the day, and for a short time period.
7. Repeat information and write down important points. Follow verbal instructions with written back up and visual aids when possible. Encourage the person to keep a notebook, electronic organizer, or calendar to track important information.
8. A participant's judgment, planning and organizational function may have an impact on the safety of operating wheelchairs, especially power-operated wheelchairs/scooters. An occupational therapist should be consulted to address issues of safe driving for individuals with MS who are experiencing cognitive problems.
9. A neuropsychology consult can be useful to define the cognitive dysfunction and work with staff and the participant to compensate for it.

Dysphagia (Swallowing Difficulties)

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

Clinical Note: Medical interventions to address swallowing problems include swallowing therapy, usually performed by a speech and language pathologist.

TIPS: Dysphagia (Swallowing Difficulties)

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

Fatigue

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

Clinical Note: Appropriate medications for the overwhelming lassitude of fatigue include amantadine, fluoxetine, modafinil, and methylphenidate.

(see TIPS for dealing with fatigue on the next page)

TIPS: Fatigue

1. A sudden increase in fatigue level is often the first sign of infection in people with MS. Monitor the individual's temperature when there is a sudden onset of fatigue. If the person has a history of urinary tract infections, it is advisable to obtain or recommend a urinalysis as soon as possible following an increase in fatigue.
2. Overheating should be avoided to minimize fatigue in heat-sensitive individuals.
3. Schedule rest periods after activity and meal periods.
4. Consult with an occupational therapist to discuss principles of energy conservation and specific energy saving techniques.
5. Meditation and other relaxation techniques may be useful in managing fatigue.
6. Fatigue can have a tremendous impact on the ability to carry out activities of daily living during the course of the day. Staff must be aware that the individual may be independent in the morning, and require a great deal of assistance by the afternoon.

Hearing and Speech Problems

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

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

Speech abnormalities are relatively common in MS. These vary tremendously from person to person. Dysarthria is the most common problem. This can range from a mild slurring of speech or alteration of the normal speech cadence to a severe dysarthria, making communication difficult. Some people with MS may also have problems with word-finding. This can slow their communication down and make ordinary conversation more difficult. Hypophonia or other problems with volume control can also be present. Speech problems often become more pronounced during times of stress or fatigue.

Pain and Sensory Disturbances

Sensory disturbances include tingling, burning and other unusual skin sensations. Some people with MS may experience hypersensitivity to touch or distorted sensations in response to touch. Sometimes ordinary touch or brushing of the skin may be painful. Many individuals experience an electric shock sensation upon flexion of the neck called, L'hermitte's phenomenon.

Pain can be caused by the sensory disturbances noted above, but can also be present as a severe aching or burning sensation. People with MS will often have "phantom pains", or sharp stabbing pains with no obvious cause. Trigeminal Neuralgia is a sudden, sharp stabbing pain in the face that lasts only a few seconds, but may re-occur frequently throughout the day.

Musculoskeletal injury can also be a source of pain in MS. People with MS often over-use their stronger muscles in favor of weaker ones, and in so doing, will injure those muscles and joints. Back pain is common, and is often caused by an abnormal gait or posture. Individuals who use walkers or wheelchairs will often develop arm and hand injuries from over-use of the upper extremities. In addition, injuries to the shoulders and back are commonly caused by care-givers during assistance in transfers. These types of pain should be treated with physical therapy, heat, anti-inflammatory medications, and other pain medicines as needed. Pain from spasticity and tight muscles is also a common complaint. (See section on spasticity.)

Clinical Note: The most effective medical treatment for pain should be geared as much as possible to the source of the pain. A careful examination, to determine the presence of injury, non-MS causes for pain, and the type of pain is essential in choosing the appropriate treatment. Many medications can be useful in controlling pain, including antidepressants, anticonvulsants, non-narcotic analgesics, and topical anesthetics. Narcotics are also used in some cases. Sometimes a pain management clinic can be helpful in controlling pain with injections.

Diminished sensation may present a safety concern in bathing and feeding (exposure to hot water, beverages, and food), smoking and use of ambulatory aides, and loss of sensation or discomfort to touch may affect a person's sexual activity.

(see TIPS for dealing with pain and sensory disturbances on the next page)

TIPS: Pain and Sensory Disturbances

1. Some people with MS may experience burning or stinging sensations on their legs and feet that may lead them to prefer to be barefoot or wear slippers rather than shoes and socks, and may worsen with weight bearing, leading them to prefer a wheel chair over walking.
2. Persons with decreased sensation and mobility impairments need to check themselves for scrapes and cuts and redness over pressure-sensitive areas as this may be a warning of a potential pressure sore.
3. Heat or ice may be effective for local pain in the muscles and joints. However, use caution when using heat as this may exacerbate symptoms.
4. Not all pain in persons with MS is from MS. Be sure to encourage the individual to work with their physician to identify the source of pain and obtain appropriate treatment.
5. Some people with MS report that massage and relaxation techniques have helped them deal with their pain but there is no research to confirm such a connection

Respiratory Muscle Weakness

Weakness of the respiratory muscles due to MS predisposes persons with MS to pulmonary infections. Persons with MS should be encouraged to receive both the influenza vaccine annually and the pneumovax (every seven to ten years). While a simple cold may not pose a problem to most people, the presence of respiratory muscle weakness and inadequate deep breathing and cough increase the risk of developing pneumonia. Individuals with weak respiratory muscles should be encouraged to focus on deep breathing exercises.

Seizures

Seizures occur only in about five percent of persons with MS and usually respond to anticonvulsant medications.

Spasticity

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

Management of spasticity may include stretching programs and prescription of antispasticity medication. Reduction of spasticity with these measures may reduce complications such as increased fatigue and pain, as well as serious problems, such as skin breakdown and contractures. If the individual has a home program of stretching, staff might be asked to assist the individual in carrying out the program at the adult day center. While many programs do not have full time rehabilitation staff, consider bringing in an OT or PT for periodic consultation and to offer ideas for group exercises that include stretching and spasticity management.

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

TIPS: Spasticity

1. Remember that muscle spasms are involuntary. Telling the individual to "relax" will not help and may even make things worse, since spasticity is often aggravated by anxiety. It is best to have the person stop whatever they are doing if possible, and wait until the spasm passes before proceeding.
2. Clonus (rhythmic jerking of the muscles, often the ankle) can often be stopped by having the individual take weight off of the jerking ankle or change position.
3. Avoid quick, sudden movements that can set off spasms. Guide the individual to move slowly and smoothly.
4. Stretching is different from the passive range of motion. It is slower and positions are held longer. It is advisable to have a qualified medical professional (physical therapist) train the staff. A typical maintenance schedule is 20 minutes three times a week. The stretching exercise program can be self-directed. It is preferable to perform stretching on a physical therapy mat for maximum stretch.
5. People with spasticity who are ambulatory should be encouraged to use a cane or walker to help stabilize balance in walking and transfers.

(TIPS for dealing with spasticity continue on the next page)

TIPS: Spasticity *(continued)*

6. Correct positioning may decrease spasticity. A physical or occupational therapist can train participants and caregivers in the best positioning techniques to control spasticity.
7. An unusual increase in spasticity may be indicative of a bladder infection or other change in metabolic status.
8. Some individuals report positive outcomes from massage therapy and other relaxation techniques. (Be sure that massage therapists are certified and obtain references if your program opts to offer this service.)

Tremor

Tremor, or involuntary shaking, can be very disabling for people with MS when it affects the limbs or head. Tremor, which appears with use of a limb, is referred to as intention tremor or action tremor and may greatly impair functions such as reaching or grasping or placement of a foot in standing or walking. This is the most common and generally most disabling form of tremor that occurs in people with MS. Like spasticity, tremor may worsen with stress.

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

TIPS: Tremor

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

Vision Deficits

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

TIPS: Vision Deficits

1. Some persons with MS 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 individual.
2. Many participants with MS will require large screen TVs to view videos or TV programs.
3. The easiest written material for persons with visual impairment due to their MS is plain black lettering on white paper in at least a size 14 font.
4. Contrasting colors on doorframes will assist persons with MS to enter and exit rooms in their power operated wheelchairs and scooters with fewer collisions.
5. Occupational therapy can help in devising adaptations for persons with visual problems.

Weakness

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

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

TIPS: Weakness

1. Use of mobility devices may offset the effects of weakness. Participants should be encouraged to use mobility aides such as canes, crutches, or wheelchairs when necessary to preserve independence.
2. Be attentive to safety when a participant comes to the program with a new (or never used) power wheelchair. If possible, have a physical or occupational therapist perform a safety evaluation and 'driver's test'.
3. There is a proper and safe technique for using mobility aids. These need to be the appropriate height and size for an individual. Proper adjustments should be made by a physical therapist.
4. Wheelchairs may have removable arm and leg rests to improve safety and independence in transferring. Power-operated wheelchairs may have hand controls, or other adaptive devices for mobilization. Choosing features for a manual or power wheelchair should be done as part of a comprehensive seating and positioning assessment. These assessments are best done at a clinic with this expertise, with both occupational and physical therapists.
5. Power-wheelchair batteries need to be recharged every evening.
6. A physical or occupational therapist can demonstrate various transfer techniques, such as stand and pivot and sliding boards, and determine which technique is most appropriate for the individual.
7. Improper transfers can lead to injuries, both to the individual and the caregiver. Be sure that all caregivers are trained in appropriate transfer methods.
8. Wheelchairs should always be in a locked position before transferring.
9. Proper body mechanics (bent knees and straight back, legs widely placed) should be used when assisting participants.
10. A belt around the waist can improve safety and function by providing something to hold on to during a transfer.

PRIMARY HEALTH CARE NEEDS

Issues that relate to good general health and wellness are often neglected in persons with MS. Symptoms that stem from a non-MS cause are often considered as just another symptom related to the disease. Health concerns of younger participants, such as menopause, may not be adequately addressed. Furthermore, some illnesses, most notably infections and other causes of fever, may affect individuals with MS in a unique way.

Help participants identify accessible health care providers in the area and encourage regular medical check-ups. People with MS should adhere to the health-screening schedule recommended for all adults:

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

Health screenings, such as mammography, are very important, particularly for this younger population, and may not be routinely provided. Difficulty positioning someone with impaired posture for a mammogram may lead to inattention to this and other important preventive health measures. Neither disability, nor the need for escort service and/or specialized transportation, should defer these screening procedures. Family members should be supported in helping their family member with MS access regular health care.

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

- ***Menstrual Cycle:*** Sometimes symptoms such as fatigue, numbness, and neuropathic pain may increase in people with MS just before menses and improve as the flow begins.
- ***Menopause:*** In women with MS, as with other women, menopause can cause uncomfortable symptoms. These have been controlled for some people with hormone replacement therapy. Recent studies have offered a new perspective on

hormone replacement therapy and the risks and benefits of such therapy should be discussed carefully with the participant.

- ***Heat and Humidity:*** People with MS can be extremely sensitive to heat and cold. Traditionally, heat sensitivity has been considered the most common problem for individuals with MS, but excessive cold can be equally troubling. Those who are heat sensitive may notice an increase in their MS problems, including fatigue, visual disturbances, balance, and strength when body temperature rises. Cooling the person down will likely restore them to their previous level of functioning, but it may take some time. People with MS who are sensitive to the cold generally find that their spasticity worsens when cold. Some individuals report other weather-related problems.

TIPS: Heat and Humidity

1. Keep the environmental controls at an even temperature.
2. Put fans in the exercise areas.
3. In the summer, encourage the use of cold packs or cloths on the neck, back, or head.
4. In the summer, encourage iced drinks or "slurpees".
5. If you are having outdoor activities, limit the time outside, make sure shaded areas are available, and make sure the transportation is comfortable before having the individuals enter the vehicle.
6. Encourage the participants to work with their physician for appropriate changes in antispasmodics in the winter.

- ***Osteoporosis:*** All individuals with multiple sclerosis should be considered at risk for osteoporosis. Long term use of steroids and physical inactivity promote osteoporosis in both men and women with multiple sclerosis. Treatment and prevention with calcium rich foods and dietary supplements (including vitamin D) as well as with osteoporosis medication is likely to be indicated. Particular care for transfers and prevention of falls is very important as fractures may occur easily and heal slowly in this population. Yearly bone density testing and monitoring by physician is recommended.

- ***Exercise:*** Some people with MS note worsening of symptoms, weakness, or even blurring of vision with exercise. Cooling strategies (wearing a cooling vest or scarf, drinking cold beverage) can alleviate these changes, caused by the temporary elevation in core body temperature. Avoid being over-zealous in organized exercise programs. Activities such as Tai chi and Aquatherapy (in cool water) are particularly popular with people with MS.

- ***Infections:*** While infections, such as urinary tract infections or flu, can precipitate acute attacks of MS, they may also produce fevers that temporarily worsen existing symptoms. This type of pseudo-exacerbation will subside as the fever subsides.

Symptoms that occur in the presence of a fever should be carefully assessed to determine whether they are indicative of a true attack that should be treated.

> **"I got very depressed and lost a lot of weight. The nurse at the day program noticed the weight loss and referred me to a counselor. I've now gained my weight back."**

- ***Hypothyroidism:*** This condition can cause slowing down, fatigue, weight gain, slowed thinking, and even neurologic symptoms that may be confused with MS symptoms. Referral to the family doctor or neurologist of the person with MS should be made if there is an unexplained worsening of symptoms.
- ***Arthritis and Fibromyalgia:*** The aches and pains of arthritis and fibromyalgia are often ascribed to MS, since about half of people with MS have nonspecific pain. Assessment of pain should consider fibromyalgia and arthritis.
- ***Insomnia:*** Sleep disturbances are common in the MS population and can exacerbate daytime fatigue. They may be related to nighttime muscle spasms, bladder disorders, pain, depression, or other factors. These disturbances in sleep must be assessed to determine specific contributing factors so that treatment may be designed appropriately.
- ***Obesity:*** Inactivity secondary to disability and depression may contribute to obesity. Treating this common health condition is challenging, as many people with MS have limitations to participating in vigorous exercise. However, exercise as tolerated, diet, and medication should be considered, since obesity may contribute to a number of other serious health disorders. Given the deleterious effects of obesity on independence for many disabled individuals, day treatment staff should monitor weight and provide a diet that meets nutritional needs and prevents serious weight gain.
- ***Immunizations:*** Recent studies indicate that influenza (flu) vaccination does not cause MS attacks or accelerate progression of the disease. Having MS should not preclude an individual from having a flu shot. The flu can be very serious in a person with MS who has compromised respiratory status, and the high fever accompanying flu may exacerbate MS symptoms. The decision should be made on an individual basis, in consultation with a physician, taking into consideration all health risks of both receiving and avoiding a flu vaccination.
- ***Pneumonia:*** Pneumonia in sedentary persons is not uncommon. Multiple sclerosis, because it can cause swallowing problems and weakness of respiratory muscles, predisposes individuals to pneumonia. When you notice individuals choking or having swallowing difficulties a referral for a swallowing evaluation is appropriate, and recommendations from that evaluation should be followed to prevent aspiration that can contribute to pneumonia.

SECTION
4

Psychosocial Issues

MS makes severe emotional demands on those living with the disease. Individuals and families are confronted with many functional and physical losses, major changes in family and social roles, and loss of control over many life decisions. Particular issues such as child rearing, marital and dating relationships, sexuality, physical attractiveness, and depression about the future (career, independence, etc.) are critical areas of concern for this younger population. Access to social work or psychiatric support is an important feature of any long-term care program that serves people with MS.

FAMILY AND CAREGIVER ISSUES

Adult day services can bring great relief to family caregivers. These services may enable family members to continue working and provide the respite necessary for emotional health. Often adult day services provide the support needed to enable the individual to remain in their own home and may delay out-of-home placement.

Most people with MS who require adult day services do not meet the traditional profile of those who generally use these services, particularly with regard to age. Their on-going care at home is most likely provided by family members. These family caregivers are also not typical. Caregivers of people with MS tend to be working spouses who may also have child care responsibilities. These MS caregivers are often too young to be eligible for many support services and may be stretched beyond their emotional and physical resources by the demands of caregiving.

Some MS caregivers are elderly parents of adults with MS. The issues that these caregivers face include their inability to manage the physical demands of caregiving as they age or become disabled themselves and the uncertainty of who will take over these responsibilities when they can no longer manage them or when they die. Some caregivers are children. While it may be appropriate for adult children to provide

care, people with MS may also be cared for by their teenagers or younger children. Whenever possible, personal care by children must be avoided. Adult day programs can provide the family with the services required to avoid placing young children in inappropriate caregiving situations.

Caregiver needs that have exceeded the resources of the family are often the prompt that leads to enrollment in adult day care. Attention to the needs of caregivers is a very important component of the adult day program. If the day care team is sensitive to family issues, the impact of stresses at home on the participant's experience can be minimized. In developing a program, planners should consider what, if any, family services and caregiver support could be provided within the context of the adult day program.

PSYCHOSOCIAL BENEFITS OF THE ADULT DAY PROGRAM

> **"I like to be around other people. Speak about problems. Not the only one. Gives you a different look at your situation."**

The emotional benefits of participating in an adult day program are many. It provides an opportunity to meet others, make friends, develop new interests, have a life outside of the home and 'something to talk about at the end of the day'. Many participants find they have something to contribute to other members of the program—sharing a particular skill or interest, supporting or advising a peer, sharing their wisdom or experience in living with MS. Doing so may offer a boost to the self esteem of a participant who has been focused on loss and the things he/she can no longer contribute. Also, activities can provide opportunities for relaxation and may have a calming affect for those with anxiety.

COPING WITH CHANGE

While each person's emotional reactions to a chronic, unpredictable disease like MS will differ, there are some fairly common emotions that the program staff would expect to encounter. These reactions will ebb and flow as the disease changes and the demands it places on the individual increase and abate. Furthermore, many individuals will experience several of these emotions simultaneously.

Grief is an ongoing, if intermittent, response over the course of the disease. From the time of diagnosis, and continuing throughout the course of the illness, the person will experience periods of grief—a normal reaction to any kind of 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 one day to the next, as well as one year to the next, people don't know how they are going to feel, what parts of their bodies are going to be affected, and what the future is going to hold for them. This kind of unpredictability makes people feel out of control of their bodies and their lives, and when people feel out of control, they get anxious. Family members share a similar anxiety over the unpredictable impact MS may have on their lives.

Resentment is another common response to unpredictability and loss of control—for both people with MS and their family members. One of the biggest challenges people face is finding a satisfactory outlet for this resentment. They need to learn how to express their anger in a constructive way, focusing it on the disease rather than each other or the doctor. Even when people with MS feel legitimate anger toward their loved ones for one reason or another, they may be afraid to express it and risk driving their partner/caregiver away. They tend to feel stuck with an anger that has no outlet.

People may also experience guilt as they deal with MS. They feel guilty about their inability to fulfill their roles and obligations in different areas of their lives. They worry that they are letting everybody down, no longer pulling their own weight. There is also guilt over uncomfortable feelings—particularly the anger toward care partners, children, and God.

TIPS: Coping With Change

Staff members can help new participants cope with change by:

1. Encouraging expression of feelings in group support settings as well as in one–one settings.
2. Encouraging friendships with veteran participants.
3. Creating an atmosphere that is welcoming to the participant's family and friends.
4. Encouraging the participant to continue to pursue former interests.
5. Participating in training to understand the psychosocial, emotional and family issues related to MS and how they can affect daily routine and relationships.
6. Understanding depression in MS and how to be sensitive and appropriately responsive.
7. Recognizing the challenge for new participants who must accomplish daily routine tasks in a new environment.
8. Encouraging participants to take a role in the governance and implementation of the program.

DEPRESSION

> “Being with other people and seeing other conditions gives me strength.”

At least 50% of people with MS will experience a major depressive episode at some point over their disease course. Because of feelings of loss, as well as neurologic changes caused by the disease itself, depression is very common among persons with MS. Fatigue—which can be an outgrowth of depression or occur as a primary symptom—frequently compounds depression in persons with MS.

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.

In NMSS-supported studies on suicide and MS, researchers concluded that the level of disability is not the key predictor of suicide risk. Rather, suicide risk was more related to a lack of connectedness with other people, and a negative self-perception of one's self, body, and future.

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

AFFECTIVE DISORDERS

Affective release (also known as “pseudobulbar affect”) refers to unpredictable episodes of laughing or crying, often having nothing to do with the person's underlying mood. It is most likely related to lesions in the limbic system or related structures. Medications are available to treat this disorder.

Emotional crescendo describes an experience in which a person becomes very emotional, crying very easily in response to any stimulus that triggers intense emotion or tension. Once the response is stimulated, it feels uncontrollable until it reaches a crescendo and resolves on its own. It differs from affective release in that the person's mood and expression are more consistent with one another. While not as upsetting or embarrassing as affective release, emotional crescendo interferes significantly with any efforts to resolve a conflict or have any kind of disagreement. Some success has been achieved with a behavioral intervention involving focused attention on the build-up of tension, deep-breathing, and relaxation to dampen or halt the response.

Euphoria, defined as a sustained mood state involving exaggerated and inappropriate happiness and optimism in the context of a very bleak situation, is generally associated with extensive cerebral demyelination and dementia. Once considered the hallmark of

MS, it is actually seen in less than 10 percent of individuals. There is no known treatment for this phenomenon; supportive interventions for the family are essential.

FINDING NEW MEANING FOR CONCEPTS OF SELF, INDEPENDENCE, AND CONTROL

A person who becomes increasingly dependent upon assistive devices, personal aides, and other forms of outside assistance needs to take pride and satisfaction in being able to identify, obtain and manage these resources. In other words, he or she needs to find new ways to think about exerting independence and control in everyday life.

> **"Adult day gets me out of the house, away from the four walls. I don't have to be by myself."**

Finding the "MS-Free Zone": Severely disabled individuals, who feel that MS has altered every aspect of their lives, need to be encouraged to look for their personal, MS-free zone where MS has not reached. For one it might be a sense of humor or love of music, for another a particular skill or talent, or a religious faith. Whatever it is, the MS-free zone provides an emotional respite from the day-to-day challenges and losses.

Spiritual Life: Living with 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 participants are important in helping them grapple with these issues.

FACTORS INFLUENCING ATTENDANCE

The ability of an individual to attend scheduled day program sessions may be influenced by a number of factors including: depression, availability of a caregiver to assist with ADLs, accessibility of the home (ability of the individual to safely enter/exit the home with or without assistance), transportation, availability of reliable child care (if participant has young children at home), limited finances, and cognitive problems which lead to forgetting scheduled days or transportation times. Exacerbations of MS also may prevent regular attendance or may lead to extended absences. It is vital to have staff inquire as to the barriers to attendance and to provide programming that addresses participants' need to feel useful and involved in community (vs. passive recipient of care). Failure to do so can also lead to poor attendance.

In addition to the emotional responses that are specific to MS, the individual with MS who attends an adult day program brings issues and related emotions from the home with them to the program. These may include parenting issues, financial worries, and

> “I live with my parents. The day program gives me my own thing.”

spouse/partner concerns. In some cases, participants may show signs of abuse or neglect and it is important for staff to be trained to recognize the risk factors and warning signs and know what action to take when suspicions of either arise.

RISK OF ABUSE AND NEGLECT

Factors associated with high risk of abuse but not precise predictors include:

- A history of family violence
- Abuse of alcohol or other disinhibiting drugs/substances
- Social isolation (from friends, family, community)
- Attitudes of devaluation and dehumanization
- Severe disability
- Chronic progressive disease that appears to exceed the caregiver’s ability to manage
- Caregivers who show signs of “burn-out,” including exaggerating caregiving involvement and MS disability
- Individuals with MS whose families are financially dependent on them
- Family members or caregivers who are under increased stress or have impaired ability to provide care because of their own health problems or other factors
- People with MS who have poorly managed mobility needs, bowel or bladder incontinence, problematic cognitive symptoms and/or personality changes, or disease worsening
- Physical dependency, making a person more vulnerable to mistreatment by others. Paid caregivers, drivers, homemakers, and others who provide assistance to people with MS may behave inappropriately and take advantage of this dependence.

Physical indicators of abuse and neglect include:

- Bruises and welts that cannot be explained by falls or bumps related to mobility problems; bruises in the shape of a hand or familiar object; bilateral bruising
- Burns that cannot be explained adequately or that are in the shape of cigarette butts
- Abrasions, e.g., marks from restraints on arms or legs
- Genital pain, irritation, itching that may be indicative of sexual abuse

- History of recurrent hospitalizations or recurrent injuries
- Poor hygiene (e.g., body odor, unkempt hair, skin, clothing)
- Improper clothing for the weather
- Bed sores and skin irritation related to soiled clothing or bed linens or not being positioned or turned regularly
- Untreated medical conditions
- Medication mismanagement, e.g., skipped doses, over-medication
- Lack of necessary mobility equipment, glasses, dentures
- Dehydration
- Malnourishment
- Mismanaged finances
- Lack of supervision
- Unexplained injuries or explanation that does not fit with observations
- Inadequate living arrangement (e.g., inadequate heat, cooling, safety, electricity, access to telephone, architectural barriers)

When abuse or neglect is identified, it is essential that staff report the situation to their supervisors and that the facility make the proper report to protective services agencies.

SECTION
5

Activities and Wellness

Therapeutic activity is the core of most adult day programs. Like seniors, younger participants with MS enjoy activities that promote cognitive, physical, social, and emotional well-being, and positive involvement in daily life. They want to engage in activities that reflect their needs, interests, functional levels, and abilities. Activities that emphasize one's abilities and can be enjoyed in spite of physical impairments are most therapeutic.

Programs that specialize in serving people with multiple sclerosis have found that offering activities that promote the various components of 'wellness' can help participants think positively about their health and well-being in spite of having a chronic illness. By 'wellness' in this context they refer to "an intentional choice of a lifestyle characterized by personal responsibility, balance and maximum enhancement of physical, mental and spiritual health—seeking a balance in lifestyle designed to improve quality of life."*

All participants want to engage in age-appropriate activities. While many interests overlap, a younger participant may want to see a different movie, learn about different topics, or listen to different music than an elderly participant. Program offerings for younger participants might include discussion sessions, support groups, and other intellectually stimulating pastimes. Accounting for varied interests is key for the provision of creative and enjoyable activities. (Information on leisure activity/interest assessment tools is included in the appendices, as well as selected activity resources.)

Educational, artistic, and cultural pursuits are essential for all participants' personal growth and well being. All participants, regardless of age, benefit from access to reading materials and music. Connectivity to the community and the world outside the program is of particularly high value to younger participants, fostered both by bringing outside resources in and bringing participants to the outside sources. Intergenerational activities and volunteer opportunities can be particularly enriching.

*Wellness materials in this section courtesy of the Marilyn Hilton MS Achievement Center, Los Angeles, CA.

Day to day changes in MS symptoms, such as fatigue and cognitive impairments, may affect the participant's degree of general function and participation in activities. Always encourage involvement in decision making to the best of his/her ability.

It is recommended that a program of therapeutic activities:

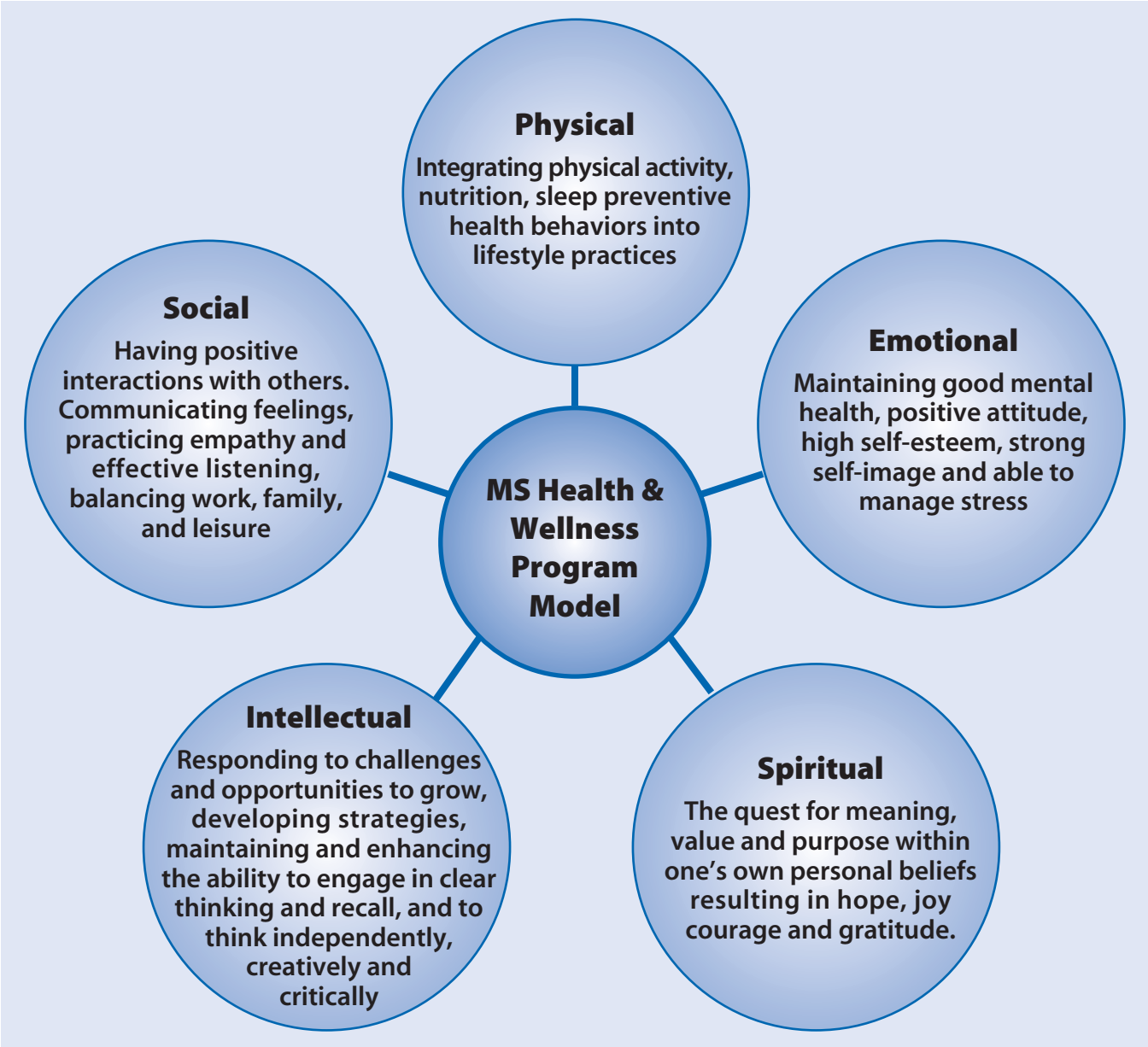
- Include a variety of individualized activities balanced with small and large group activities
- Provide a balance of active and spectator participation
- Provide intergenerational experiences
- Involve interaction with the community
- Involve outdoor activities as appropriate
- Involve cultural and ethnically diverse celebrations
- Support self-care and other ADL activities
- Enhance knowledge and skills
- Support and encourage interpersonal relationships
- Enhance self esteem, self confidence and mood
- Offer a positive outlet for energy, emotions and self-expression
- Tap into creative capacities
- Be balanced with rest and relaxation
- Be fun and enjoyable
- Support physical and emotional health and wellness
- Support self-determination and provide opportunities for participant governance

Integrating persons with MS into an elderly-focused day program may have its challenges. There will probably need to be more focus on physical assistance, personal accommodations, and supervision. There may be cultural attitudes about disease and disability that need to be addressed. Space limitations may have an impact. However, focusing on inclusion and integration emphasizes similarities over differences and has been found to enrich the experience for all involved.

> **"We have a young adult group at the center. We decide movies, have discussions, plan parties, and go shopping."**

A FOCUS ON WELLNESS

Activities that support personal empowerment and growth, i.e., 'wellness' activities, can be categorized in terms of physical health, social health, emotional health, intellectual health and spiritual health. The diagram on the next page describes these aspects of overall health and well-being.



Here are some examples of activities in each one of these domains:

- ***Physical Health:*** Group exercise, Yoga, education and training in self-care, medication management, nutrition education, symptom management, personal health advocacy
- ***Social Health:*** Field trips, dining out, shopping, cooking activities, discussions on areas such as communication and family relationships
- ***Emotional Health:*** Peer counseling, group therapy, pet therapy or assistance with an in-house pet, volunteer work, stress management, sharing personal knowledge and expertise ("giving back")
- ***Intellectual Health:*** Current events discussions, lecture series, book discussions, films, computer activities, writing and journal programs, resident council participation, continuing adult education
- ***Spiritual Health:*** Meditation, relaxation, expressive therapies, guided imaging, religious activities, discussions

COMMUNITY ACTIVITIES AND ACCESSIBILITY

People with MS are usually younger and often have stronger ties to the community than the frail elderly. They appreciate attending community events, shopping at a mall, or engaging in volunteer opportunities in schools, homeless shelters, and other settings.

> "I love to get out in the community. Travel, even just to the adult day center, is an adventure."

It is important to remember that trip planning requires careful consideration of accessibility and appropriateness of destination (stairs, bathroom accommodations, etc.). Even though a site may tell you they are 'accessible' on the phone, the reality may be a different story entirely. Check out destinations in advance if possible. Consider carefully the needs of the individuals who will attend. What equipment, medications, assistive devices must you bring along? What are the safety considerations? Planning for all eventualities will assure a safe and enjoyable trip.

AFFIRMING ACTIVITIES

Opportunities to 'give' to others, e.g., teach a skill, help plan an activity, give a talk about a topic of expertise, lead a current events discussion or book group, all support an individual's self-confidence and esteem and help to build community within the program. Therefore adult day staff is encouraged to look for ways in which the person with MS can feel useful and contribute to the program.

COMPUTERS

Computers are an important part of life for younger participants with MS. Therefore computer-based activities may be of great interest to this population. Minimal adaptations to computers (e.g., enlarged keyboard) may make these activities accessible to a larger number of participants. Contact local computer training schools for possible donations of expertise, time, hardware, software, computer modifications, etc. If a day program has the interest and resources, more elaborate adaptations can be assessed and prescribed by an occupational therapist or assistive technology specialist.

> "I like being around younger people, whether they have MS or not."

Determining activities that are most appropriate for each participant involves assessment of leisure interests and wellness goals. By framing participation in activities as strategies to achieve wellness in various domains of life, in spite of a chronic illness, the adult day program can offer a positive, hopeful and therapeutic environment for participants.

SECTION
6

Rehabilitation

Rehabilitation services are consistently cited as a high priority for people with MS. These therapies represent an opportunity to maximize overall health, comfort, and independence.

Some adult day programs may have rehabilitation professionals on staff, others contract with therapists from community agencies and still others may refer clients when there is a distinct need. Whatever your staffing may be, the activities at your program can support many of the rehabilitation needs of your participants. Programs that do not have on-site rehabilitation services may help their participants access these services by bringing in therapists for monthly rounds and rehabilitation clinics, by working with the local National MS Society chapter to contract with a rehabilitation consultant, and by working with local hospitals, home health agencies and OT/PT practices in the community.

REHABILITATION REFERRAL

Refer participants to physiatrists, neurologists, occupational therapists (OTs), physical therapists (PTs), speech and language pathologists (SLPs), neuropsychologists, psychiatrists, and other appropriate professionals (e.g., orthopedists, orthotists, assistive technology experts) to provide support in complex situations. These health professionals can offer a customized approach to assessing mobility, positioning, feeding, and equipment needs as well as therapeutic exercise and training. You may want to refer the participant to these rehabilitation professionals if you notice changes in mobility, slurred speech or an increase in difficulty communicating, swallowing difficulty, an increase in stiffness or spasticity, increased tremors, fatigue interfering with functioning, etc. Ideally, identify therapists in your community who have experience with MS.

Physical therapy (PT) can help strengthen weakened or uncoordinated muscles, and improve balance. PT might include range-of-motion exercises, stretching, strengthening, assistance with walking, and the best ways to be fitted for and to use canes, walkers, wheelchairs, or other assistive devices. PT can also include exercises to increase overall function and stamina.

> "I love to do things that can make me feel stronger, such as exercise classes and physical therapy."

Occupational therapy (OT) is geared toward maintaining or improving independence in both basic and instrumental activities of daily living. OT includes teaching compensatory techniques for both physical and cognitive (thinking) problems, energy conservation techniques, strengthening methods, building tolerance for activity, and improving ability to perform a full range of everyday activities (e.g., dressing, transfers, home management activities, driving). Occupational therapists provide recommendations and training for activity and environmental modifications, and assistive devices to facilitate function

> "Occupational therapy is very important to me. Helps with upper body strength."

Speech therapy (ST) may improve communication for those who may have difficulty speaking or swallowing due to weakness or poor coordination. Techniques used by speech/language therapists (also called speech/language pathologists (SLP) might include exercise, voice training, or the use of special devices.

Cognitive rehabilitation offers strategies to improve or compensate for problems with memory, attention, information processing, and reasoning. Cognitive rehabilitation sessions may be with a neuropsychologist, speech/language pathologist, or occupational therapist.

GROUP EXERCISE

Group exercise can provide the opportunity for socialization and peer support as well as therapy (e.g., stretching, range of motion) and skills training (e.g., transfer training, ADL training). It is advised that you have a therapist review your group exercise programs to be sure you are considering the special needs of participants. Other group movement programs can augment more traditional exercise programs. For example, T'ai Chi, Yoga and other complementary therapies may enhance the benefit of group exercise.

WHEELED MOBILITY

Their younger age and developmental stage in life generates a great need and desire for mobility to socialize, gain access to the community, and participate actively in the adult day program and in the community. The nature and extent of MS disability has an impact on the type of wheelchairs needed, as well as the type and placement of wheelchair controls, transfer aids (e.g., lifts), beds and other mobility equipment.

Because of severe physical disability (weakness, paralysis, tremors, spasticity, fatigue, sensory deficits, incoordination, visual deficits, etc.), people with MS frequently require power wheelchairs with tilt and recline capabilities, wide dimensions, customized positioning, and customized drive controls. They may 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. Proper positioning can improve comfort, independence, and mobility as well as prevent secondary complications such as skin breakdown, postural deformities/contractures, and compromised breathing.

Ensuring that an individual obtains the right type of wheeled mobility (manual or power), with the features that are most appropriate for his/her physical, cognitive and environmental situation is critical and complex. Referral to a specialized seating and mobility clinic will provide the greatest likelihood of ensuring that a person with MS obtains the best and most appropriate wheeled mobility device. Given the restrictions that insurance companies often place on the wheeled mobility, the importance of these comprehensive assessments cannot be overstated.

> **"I like being around people with MS, regardless of their age."**

It is important that staff understand the proper use of the wheelchairs, how to charge power chairs, and the proper use of devices such as splints. Wheelchairs are often costly and complex machines that require on-going care 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). Staff need to understand proper positioning, e.g., the wearing schedule of splints, checking for skin breakdown or irritation, and proper use of other positioning. They also need to monitor the participants' ability to safely mobilize their wheelchairs or scooters and note when a referral for new equipment may be appropriate.

Individual rehabilitation plans should be created after initial assessment of function and re-visited frequently as MS changes and the needs and priorities of the individual change.

A listing of rehabilitation assessment tools for MS is included in the appendices of this document.

SECTION
7

Staffing and Physical Plant Issues

STAFFING ISSUES

Careful consideration must be given to a variety of staffing-related issues when providing adult day services for persons with MS. Most center staff are skilled in addressing the needs of older adults and/or younger adults with intellectual/developmental disabilities. There are, however, a number of unique concerns that emerge when serving a younger, mentally alert adult population with MS. This includes staff-to-participant ratio, orientation and ongoing training, the need for supervision and support, along with an interdisciplinary approach.

Staff Ratios

Given the unpredictability of MS, centers need to closely monitor both the overall participant-to-staff ratio as well as the ratio of direct care staff (those who assist with transfers and personal care along with some basic nursing needs) relative to other program staff. Centers may wish to consider implementation of a "level of care" based model to determine the appropriate number and type of staff available on any given day.

In this model, standardized assessment tools can be utilized to rate each individual enrolled according to the center's staffing needs. For example, higher scores are given for those individuals who require assistance with transfers or for those who are incontinent of bowel and/or bladder. Center directors are then better able to adjust staff levels based on projected participant needs. Due to the changing nature of MS, persons with MS may require more frequent reassessments of their level of care needs.

Volunteers

Some programs augment staff with volunteers and students. This provides a learning opportunity as well as provides extra hands to implement the program.

Sources of volunteers include:

- Aging advocacy groups, Area Agencies on Aging, National Council on Aging, American Society on Aging, Retired Senior Volunteer Programs (RSVP)
- Schools: elementary and middle schools, high schools, universities, technical schools
- Businesses (a source of volunteers for special events)
- Volunteer organizations, parishes, synagogues
- Civic organizations such as the Chamber of Commerce, Kiwanis, Rotary, and Lions Clubs
- Garden clubs

Staff Orientation/Training

It is unlikely that staff in the adult day setting will have extensive prior experience or knowledge of MS. Therefore it is essential that a thorough orientation, along with comprehensive ongoing training, be provided so that all staff can collectively deliver a high standard of care to meet participant needs and be responsive and sensitive to the particular issues and challenges that are part of living with MS. The National Multiple Sclerosis Society is an excellent resource to you as you plan staff training. They can often provide speakers, materials, and ideas for providing effective training. Call 1-800-FIGHT-MS to be connected with your local NMSS chapter.

As previously noted in Section 4, MS makes severe emotional demands on those living with the disease. Individuals are confronted with many functional and physical losses, major changes in their family and social roles, and loss of control over many life decisions. Training that encourages staff to create opportunities for persons served to participate in the governance of the program and the selection of activities will help foster self-determination. The participant should be allowed as much choice and independence as possible without compromising safety.

It is recommended that the following topics, as a minimum, be included as part of the education and training protocols for staff:

- ***MS: The Disease***

  1. The fundamentals of MS, including the disease process, manifestations, and management of the disease and its symptoms. The National MS Society is an excellent resource for training materials and trainers.

2. The unpredictable nature and often progressive course of MS; staff may see variability from day to day as well as increased disability occur over time and will need to be prepared to be flexible about changing needs.
3. The difficulties managing symptoms such as fatigue, tremors.

> **"The social workers are very helpful. You can talk to them about your problems. They help you with things like housing, Medicaid, family problems . . . ."**

Psychosocial Issues

1. Understanding the psychosocial, emotional and family issues related to MS and how they can affect daily routines and relationships.
2. The role of depression in MS and how to be sensitive and appropriately responsive.
3. Recognition of the challenge for new program participants who must accomplish tasks in a new environment.
4. Establishing professional boundaries between staff (including drivers), volunteers, and a participant who may be looking for a romantic or sexual relationship.

Mobility

1. Proper use and care of assistive devices: walkers, canes, wheelchairs (manual and power).
2. Specific safety risks that can occur with people with MS.
3. Proper techniques for assistance with transfers including sit to stand, stand to sit, and on/off the toilet.
4. Recognition that persons with MS are often heavier and less frail than geriatric participants.

ADL Management

1. Ability to properly assist a participant to perform activities of daily living.
2. Attention to sensory deficits that may make the participant at risk for burns, scrapes, and pressure sores; knowledge of performing skin checks.
3. Offering as much choice and independence as possible regarding ADLs and therapeutic activities.
4. Focusing on age-related ADLs that are not frequently seen in elderly participants. (These may include shaving and leg waxing, or applying daily make-up; younger women may still be menstruating and will require assistance with management of their periods.)

- ***Monitoring of Health Status***

  1. Medical management unique to MS (cognitive problems, spasticity and immobility, skin integrity, pain, fatigue, heat intolerance, and bowel and bladder management).
  2. Identification of safety risks and needs that must be communicated to appropriate administrative staff promptly.

- ***Cognitive Issues***

  1. Differentiation of the cognitive issues of MS with the dementia of the elderly.
  2. Addressing potential behavioral and cognitive problems that may be a consequence of the progression of MS (e.g., the feeling of loss of control that often accompanies severe MS, resulting in the participant compensating for such loss by trying to control people around him/her or by angry outbursts).

Staff Supervision and Support

Staff burnout may become a significant issue as serving persons with MS can be both physically and emotionally demanding. Centers may wish to explore interventions such as regular one-on-one supervision, staff support groups, periodic 'processing' meetings and retreats, along with opportunities for flex time, job sharing, and rotation of duties. This, in combination with the staff education and training outlined above, can help to address the issue of staff burnout. It is important for all staff to be reminded of their need to take care of themselves in order for them to continue to be effective in their ability to provide support and care for others.

Interdisciplinary Approach

Finally, due to the complex and changeable nature of MS, it is recommended that centers utilize a multidisciplinary approach that includes professions such as nursing, social work, rehabilitative therapies (occupational therapy, speech therapy, physical therapy), therapeutic recreation, dietary nutritional counseling, and pastoral care. In addition, there is an increasing body of knowledge that highlights the potential value of a number of alternative therapies and the use of the expressive/creative arts (massage therapy, yoga, music therapy, etc.).

PHYSICAL PLANT ISSUES

Barrier-free, safe facilities are an important requirement for all program participants. Meeting ADA guidelines are a minimum standard. Also, licensure requirements, fire safety codes, and other state regulations will dictate physical space specifications. The

National Adult Day Services Association and the National Council on Aging Institute on Adult Day Care have each developed facility standards that should be met or exceeded.

Below are some key physical plant issues for individuals with MS:

- Hand rails
- Non skid flooring or very low pile carpeting
- Adjustable heat and air conditioning
- Specialized active or passive cooling equipment—passive cooling equipment (gel based freezer packs; Steele brand type vests) can be used if freezer space can accommodate extra cooling gel packs; active cooling (cooled fluid flows through a vest and hat) equipment can be larger and potentially noisy
- Wheelchair-accessible activity areas and several bathrooms
- Water temperatures in bathrooms at safe levels
- Bathrooms accommodated with items for emptying leg bags
- Adequate space to maneuver a walker, wheelchair or scooter
- Grab bars, hand rails, accessible door pulls
- Adjustable activity and dining tables that adapt to different wheelchair heights
- Fabrics and materials that are easily cleaned and flame retardant
- Secure area to store medical records, medications, etc.
- Accessible outdoor areas with covered areas to provide protection from the sun
- Participant access to telephones (large buttons, volume control, hands-free dialing), light switches, drinking fountains, door knobs (levers), etc.
- Covered, adequate, accessible drop-off and pick-up areas outside;
- Accessible private and quiet rest areas
- Accessible private areas for conferences with participants and/or their families
- Adequate storage space
- Kitchen facilities that provide safe and sanitary handling and storage of food
- Call lights in bathroom and rest areas
- Roll-in showers, if provided
- Rehabilitation equipment appropriate for participants, e.g., standing frames, parallel bars, weights, etc.
- Laundry facilities
- Elevators or one-level floor plan; oversized elevators that can accommodate several wheelchairs at a time (including electric wheelchairs) are an important feature

For those programs that have the resources to consider a dedicated exercise/fitness area, these are items to consider:

- A large exercise area/room in order to accommodate the maximum amount of wheelchairs for group exercise instruction
- Floor mats for out-of-chair exercise, stretching, yoga, etc.
- A folding, wall mounted mat table for range of motion/strength training, etc. and for enabling safe transfer (for client and staff) from manual and power wheelchairs and scooters
- Small hand weights and fastening wrist/ankle weights for individuals with grip strength deficiencies
- Power Trainer type arm and leg ergometers for aerobic conditioning and active/passive upper body; cycle-type ergometers for range of motion for clients that are unable to hand/foot pedal (but can still receive benefit from ROM/aerobic conditioning)
- The 'usual' rehab equipment for work on ADL's and other specific exercises (standing frames, therabands, grip balls, stability (Swiss balls), stretching aids (blocks and cords) as well as the aforementioned cooling equipment
- Commercial treadmills with bilateral arm rails. Some treadmills are equipped with balance aids or other devices
- Adjustable parallel bars that allow clients to gait train in a safe environment
- Access to an accessible therapy pool that is not warmer than 84 degrees

TRANSPORTATION

Transportation often presents a significant challenge to many programs. Reliable transportation is key to program participation. Some programs contract with local wheelchair transit companies, while others may have their own vans or busses. Still others may rely on county or town paratransit services.

Paratransit services are transportation services for the disabled that the community must provide to be in compliance with the American with Disabilities Act (ADA). The ADA guarantees that people with disabilities have the same access to public services such as transportation as people without disabilities. Public bus services are expected to provide buses with wheelchair lifts and other special devices. Curb to curb service may also be available, although the person with a disability must be able to be out of their house and on the sidewalk for pickup.

Since many people with MS use large, power wheelchairs, you must be certain that tie-downs and other safety features can accommodate these wheelchairs. Furthermore, air-conditioning is absolutely required for participants with MS. Drivers may require

specialized training if serving a younger population with significant disability and complicated wheeled equipment. Medicaid will often cover transportation expenses to medical appointments and services.

Because fatigue is a significant factor for many participants with MS, the time it takes to be transported to and from the program must be considered when determining if the program will be appropriate and practical to attend.

Practical information about community-based accessible transportation services for people with disabilities can be found at: www.projectaction.org.

APPENDIX
A

Intake and Assessment Tools

SAMPLE INTAKE/ASSESSMENT APPLICATION

The following is the intake/assessment application for the Marilyn Hilton MS Achievement Center, a specialized day program for people with MS. This intake tool was developed by the Center to particularly highlight issues relative to MS and to help the provider have a clearer picture of the impact of MS on the applicant. This model assessment tool can be adapted for your program's needs and provide you with practical information that will be helpful in the development of an individual care plan.

For Internal Use Only
Intake: ____/____/____
Start: ____/____/____

MSAC Day Program Member Application, Part One

Name: _____ Date: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: Home: _____ Work: _____ Cell: _____

E-mail address: _____ Fax: _____

Gender: ❑ Male ❑ Female Handedness: ❑ Left ❑ Right ❑ Both

Date of birth: ____/____/____ Soc. Sec. # _____

Emergency Contact: _____
(name/relationship) (phone #)

Social Information

Place of birth: _____

Do you use tobacco? ❑ Yes ❑ No
If yes, indicate type, amount and for how long: _____

Do you consume alcohol? ❑ Yes ❑ No
If yes, indicate type, amount and for how long: _____

Total years of formal education:
❑ Grade School (1–8) ❑ High School (9–12) ❑ College (13–16)
❑ Masters (17–18) ❑ Doctorate (19–20)

Marital status:
❑ Single (never married) ❑ Married ❑ Domestic Partner
❑ Separated ❑ Widowed
❑ Other: _____

Who lives with you at the present time?

❑ Spouse/Domestic Partner ❑ Children: Age(s): _____

❑ Parent(s) ❑ Brothers and/or Sisters ❑ Other Relatives ❑ Friends

❑ Live Alone ❑ Other: _____

Type of residence:

❑ House ❑ Condo/Townhouse ❑ Apartment ❑ Other: _____

Home accessibility:

❑ Stairs into home: # of Stairs: _____ Railing ❑ Yes ❑ No

❑ Stairs within home: # of Stairs: _____ Railing ❑ Yes ❑ No

❑ Elevator ❑ Ramp ❑ Other (describe): _____

Transportation:

❑ Self ❑ Family/Friend (name and phone #): _____

❑ ACCESS (ID#): _____ ❑ City Ride ❑ Public Transportation

❑ Other (describe): _____

Employment Information

Have you ever held a job? ❑ Yes ❑ No

What is your current employment status?

❑ Employed full-time ❑ Unemployed ❑ Retired

❑ Employed part-time ❑ Unemployed d/t MS ❑ Retired d/t MS

❑ Employed part-time d/t MS ❑ Student

❑ Other: _____

If employed, what kind of work do you do? _____

Describe any problems your MS is causing in terms of your work or school: _____

_____

_____

Medical Information

Insurance info: ❑ PPO/POS _____ ❑ HMO _____

❑ Medicare _____ ❑ Medi-Cal _____

❑ Other _____ ❑ None

Primary Care Physician: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ FAX: _____

Neurologist: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ FAX: _____

Date of onset of initial symptoms of MS: _____

Date of MS diagnosis: _____

Does anyone else in your family have MS? ❑ No ❑ Yes If yes, whom? _____

The following is a list of symptoms some people with MS have experienced. Not everyone who has MS experiences these symptoms so please do not read anything into this list. Please check off only the symptoms you are currently experiencing:

- ❑ Visual changes
- ❑ Changes in sensation
- ❑ Pain
- ❑ Tremors
- ❑ Spasticity (muscle stiffness)
- ❑ Impaired coordination
- ❑ Muscle weakness
- ❑ Impaired balance/dizziness
- ❑ Bladder problems
- ❑ Bowel problems
- ❑ Changes in sexual function
- ❑ Fatigue
- ❑ Heat sensitivity
- ❑ Changes in speech/swallowing
- ❑ Memory or other cognitive changes
- ❑ Falls in Last 6 Months

  How Many? _____

❑ Emotional Changes (feelings of sadness, hopelessness, changes in appetite/sleep)

(describe): _____

❑ Other (describe): _____

Please indicate any ***changes*** in your MS symptoms you have noted in the ***last 6 months***:

_____

_____

List the ***3 areas that are the most challenging*** to you in respect to MS (list the most challenging area first):

1. _____

2. _____

3. _____

List any mobility devices you currently use:

- ❑ Single point cane
- ❑ 4-prong cane
- ❑ Pick up walker
- ❑ Front-wheeled walker
- ❑ 4-wheeled walker
- ❑ Manual wheelchair
- ❑ Power wheelchair
- ❑ Scooter
- ❑ Lofstrand crutches
- ❑ Axillary crutches
- ❑ Ankle foot orthosis (AFO)
- ❑ Other (describe): _____

List any other assistive equipment you currently use:

- ❑ Glasses/contact lenses
- ❑ Hearing aid(s)
- ❑ Grab bars at toilet
- ❑ Grab bars in tub/shower
- ❑ Raised toilet seat
- ❑ Shower chair
- ❑ Commode chair
- ❑ Tub bench
- ❑ Indwelling (Foley) catheter
- ❑ Hand-held shower hose
- ❑ Intermittent catheter
- ❑ Long-handled sponge
- ❑ Sliding board
- ❑ Other (describe): _____
- ❑ Hoyer lift
- ❑ Hospital bed

Do you have any other medical problems? ❑ Yes ❑ No

If yes, check all that apply:

- ❑ Abnormal bleeding
- ❑ High blood pressure
- ❑ Arthritis
- ❑ High cholesterol
- ❑ Asthma
- ❑ Osteoporosis
- ❑ Back pain
- ❑ Seizures
- ❑ Cancer
- ❑ Stroke
- ❑ Depression
- ❑ Thyroid disease
- ❑ Diabetes
- ❑ Other: _____
- ❑ Heart disease: ❑ Heart attack ❑ Chest pain ❑ Irregular heart beats ❑ Fainting

Please list all hospitalizations, operations and injuries, including broken bones (include dates):

Allergies: ❑ None ❑ Drug ❑ Food ❑ Iodine ❑ Latex ❑ Other _____

Describe: _____

_____

Diet restrictions:

❑ None ❑ Diabetic ❑ Low sodium ❑ Low fat ❑ Other _____

Are you currently taking any of the MS treatment medications?

❑ Yes ❑ No If yes, check all that apply:

❑ Avonex ❑ Betaseron ❑ Copaxone ❑ Rebif ❑ Novantrone

Current Prescribed Medications:

Name	Dosage	How Often?	Purpose

Over the Counter Medications, Vitamins, Herbs and Supplements:

Name	Dosage	How Often?	Purpose

Exercise History

Do you currently exercise? ❑ Yes ❑ No

If yes, please indicate your current exercise program:

Activity	Distance/Duration	Frequency per Week

If you do not currently exercise, have you exercised in the past? ❑ Yes ❑ No

If yes:

What did you do for exercise? _____

When did you stop exercising? _____

Why did you stop exercising? _____

How would you rate your overall knowledge about MS:

❑ Poor ❑ Fair ❑ Good ❑ Very Good ❑ Excellent

How would you rate your overall level of wellness:

❑ Poor ❑ Fair ❑ Good ❑ Very Good ❑ Excellent

Why did you choose to come to this program?

Please state one (or more) personal goal(s) that you would like to accomplish in this program.

1.

2.

3.

MSAC Day Program Application, Part Two: Functional Abilities

Please check off the level of difficulty, if any, you have with the following activities.

1) ***Stair climbing.*** Walking up and down a flight of 12 stairs.
   - ❑ Unable to perform
   - ❑ Need human assistance to perform
   - ❑ Need cane, brace or railing to perform
   - ❑ Some difficulty, but performed without aid
   - ❑ No difficulty, able to perform without railing

2) ***Mobility.*** Walk 150 feet without rest on level ground or indoors.
   - ❑ Unable to perform or requires someone to push manual wheelchair or requires power wheelchair to perform
   - ❑ Need human assistance or can use manual wheelchair independently to perform
   - ❑ Need cane, brace or walker to perform
   - ❑ Some difficulty, but performed without aid
   - ❑ No difficulty

3) ***Transfers.*** Transfer to and from toilet, chair, wheelchair and bed.
   - ❑ Must be lifted or moved about completely by another person or by equipment
   - ❑ Need human aid to perform
   - ❑ Need adaptive or assistive devices such as grab bars, sink or sliding board
   - ❑ Some difficulty but performed without aid
   - ❑ No difficulty

4) ***Bowels.*** Able to manage constipation and control bowels.
   - ❑ Has *frequent* loss of bowel control
   - ❑ Need enemas or suppositories administered by another, or has *occasional* bowel incontinence
   - ❑ Need regular (more than once per week) laxatives, enemas or suppositories that are self-administered
   - ❑ Some difficulty requiring high fiber diet or occasional laxatives, enemas or suppositories
   - ❑ No difficulty

5) ***Bladder.*** Able to control bladder function.
   - ❑ *Frequent* loss of bladder control (incontinence)
   - ❑ *Occasional* incontinence and/or use of indwelling catheter or external catheter applied or maintained by others; and/or intermittent catheterization performed by others

- ❑ *Frequent* hesitancy, urgency or retention*, and/or use of indwelling or external catheter applied or maintained by self, and/or intermittent catheterization by self *(*Hesitancy is difficulty initiating urination; urgency is need to urinate immediately; retention is inability to empty bladder completely)*
- ❑ *Occasional* hesitancy or urgency
- ❑ No difficulty (even if maintained by medication)

6) ***Bathing.*** Able to transfer in and out of tub or shower and bathe self.
- ❑ Unable to perform
- ❑ Need human assistance to transfer or to bathe
- ❑ Need assistive devices (shower chair, tub bench, grab bars) to bathe self
- ❑ Some difficulty with washing and drying self but able to perform without aid either in tub, shower or by sponge bathing
- ❑ No difficulty

7) ***Dressing.*** Able to dress and undress using standard clothing and shoes.
- ❑ Unable to dress self
- ❑ Need *human assistance*, but performs most of activity independently
- ❑ Need specifically *adapted clothing or shoes* (no buttons, front-closing garments, no zippers, Velcro closures) or avoids certain types of standard clothing or shoes, or uses devices (long shoe horns, button hook, zipper extenders) to dress self
- ❑ Some difficulty dressing self in standard clothing, but able to perform by self
- ❑ No difficulty

8) ***Grooming.*** Able to brush teeth, comb hair, shave and apply cosmetics.
- ❑ Almost all tasks are performed by another
- ❑ Need *human assistance* to perform some tasks
- ❑ Need for *adaptive devices* (electric razor or toothbrush, special combs or brushes, arm supports) but able to perform without assistance
- ❑ Some difficulty, but all tasks performed without aid
- ❑ No difficulty

9) ***Feeding.*** Able to use standard utensils to feed self and consume solids and fluids.
- ❑ Unable to feed self
- ❑ Need *human assistance* to eat or requires modified diet (thickened liquids, pureed foods)
- ❑ Need for *adaptive devices* (special utensils, plates, cups, straws) or special preparation (cut up foods, butter bread, open containers)
- ❑ Some difficulty, but able to perform by self
- ❑ No difficulty

10) ***Vision.*** Able to read print finer than standard newspaper print with glasses if needed.
- ❑ Legally blind
- ❑ Can only read *very* large print such as headlines, or has constant double vision, or objects seem to move when looking at them
- ❑ Need magnifying lenses or large print to read, or double vision interferes with seeing
- ❑ Cannot read print finer than standard newspaper print even with glasses, or complains of double vision
- ❑ No difficulty; can read print finer than standard newspaper print with glasses if needed

11) ***Speech and hearing.*** Able to speak and hear clearly for communication with others.
- ❑ *Severe* deafness and/or slurred speech without techniques or aids to effectively compensate.
- ❑ *Severe* deafness and/or slurred speech *that is managed* using sign language or self-written communication
- ❑ *Moderate* hearing loss requiring hearing aid and/or moderate slurred speech that interferes with communication, and/or needs communication aids such as special keyboards
- ❑ *Mildly* impaired hearing or speech that does not interfere with communication
- ❑ *No difficulty* with hearing, speech or communication

12) ***Mood and thought problems.*** Includes feeling sad or blue, nervous or tense, rapid mood swings and/or angry outbursts.
- ❑ Mood or thought problem *severely* interferes with day-to-day functioning
- ❑ Mood or thought problem *moderately* interferes with day-to-day functioning and requires medications and/or on-going assistance of psychiatrist, psychologist, social worker or counselor
- ❑ Mood or thought problem *mildly* interferes with day-to-day functioning but can be managed with medications and/or assistance of mental health professionals
- ❑ *Occasional* mood or thought difficulty, but does not interfere with day-to-day functioning
- ❑ *No difficulty*

13) ***Intellectual functions.*** Includes memory, reasoning, calculation, judgment and orientation to perform everyday activities.
- ❑ Severe confusion, disorientation or memory loss that prevents performance of most everyday activities
- ❑ Need to be prompted or assisted by others to perform everyday activities
- ❑ Need to use lists or other cues to perform everyday activities, but able to do so without help of others
- ❑ Mild difficulty, but does not interfere with everyday activities
- ❑ No difficulty

14) ***Fatigue.*** Overwhelming weakness or loss of energy that interferes with physical function.

- ❑ Fatigue prevents *prolonged* physical function
- ❑ Causes *frequent* problem with physical function
- ❑ Causes *mild* or passing problem with physical function
- ❑ *Present, but does not interfere* with physical function
- ❑ *No fatigue*

15) ***Sexual activity and function.*** Ability to engage in acts that cause a sexual response.

- ❑ Sexually *inactive* and not concerned
- ❑ Sexually *inactive*, but wishes to regain previous pattern and ability
- ❑ Sexually *less active* than before, and now experiencing some sexual problems; wishes to regain previous pattern and ability
- ❑ Sexually *less active* than before and/or now experiencing some sexual problems, but not concerned
- ❑ Sexually *active* as before and/or not experiencing sexual problems

16) ***Do you have a caregiver?*** ____ Yes ____ No

If yes, please indicate number of hours per day and types of assistance caregiver provides:

Functional and Health Assessment Measures in MS

While the following list is not intended to be comprehensive, it represents many of the tools commonly used in rehabilitation and disability assessment of patients with MS.

- ***Ashworth and Modified Ashworth Spasticity Scale:*** These are ordinal scales of tone intensity. The Ashworth rates tone on a scale of 0–4, while the Modified Ashworth was developed to further define the lower end of the scale making it more discrete by adding the grade 1+. Reference: Lee K.C., Carson L., Kinnin E., and Patterson V. "The Ashworth Scale: A reliable and reproducible method of measuring spasticity." *J Neuro Rehab* 1989; 3: 205–209.

- ***Barthel Index:*** An ordinal scale of function in ten areas encompassing mobility, ADL function, and continence. Reference: Mahoney F.I. and Barthel D.W. "Functional evaluation: The Barthel Index." *Maryland State Medical Journal* 1965; 14: 61–65.

- ***Berg Balance Scale:*** An ordinal scale of balance that is sensitive to change. Reference: Berg K., Wood-Dauphinee S., Williams J.I., and Maki B. "Measuring balance in the elderly: Validation of an instrument." *Can J Public Health* 1992; Jul–Aug Suppl 2: S7–11.

- ***Box and Block Test of Manual Dexterity (BBT):*** The Box and Block test was originally developed to evaluate the gross manual dexterity of adults with cerebral palsy. The test is made up of a box with a partition directly in the center creating two equal sides. A number of small wooden blocks are placed in one side of the box. The subject being tested is required to use the dominant hand to grasp one block at a time and transport it over the partition and release it into the opposite side. The subject is given 60 seconds in which to complete the test, and the number of blocks transported to the other side is counted. The test is then repeated with the non-dominant hand. It is suitable for persons with limited cognition and manual dexterity. Reference: Mathiowetz V., Volland G., Kashman N., and Weber K. "Adult norms for the box and block test of manual dexterity." *Am J Occup Ther* Jun 1985; 39: 386–391.

- ***Canadian Occupational Performance Measure (COPM):*** An individualized, client-centered outcome measure focusing on three areas: self-care, productivity and leisure. Information about this measure can be found at www.caot.ca/copm/index.htm.

- ***The Dallas Pain Questionnaire:*** The Dallas Pain Questionnaire was developed to assess the amount of chronic spinal pain that affects daily and work activities, leisure activities, anxiety-depression, and social interest. There is a 16 item self-report that takes about 5 minutes to complete. Each item contains its own visual analog scale. The scales are divided into five to eight small segments in which the subject is asked to mark an "X" which indicates where his or her pain impact falls on the continuum. The visual scales are anchored at the beginning with words such as "no pain" and 0%, close to the middle "some," and at the end with "all the time" and 100% impact of pain. Reference: Lawlis G., Cuencas R., Selby D., and McCoy C.E. "The development of the Dallas pain questionnaire." *Spine* 1989; 14(5): 511–516.

- ***Functional Independence Measure (FIM):*** An ordinal scale of functioning in multiple areas including feeding, grooming, bathing, dressing, toileting, transferring, locomotion, comprehension, expression, social interaction and problem solving. Information about obtaining the FIM may be obtained from Uniform Data for Medical Rehabilitation UB Foundation Activities, Inc. at 716-817-7800 or www.udsmr.org.

- ***Health Status Questionnaire (SF-36):*** This is a 36-item patient self-report regarding the patient's perception of health and physical limitations. It is widely used in the US. It is a component of the MSQLI. It is a registered trademark of the Medical Outcomes Trust, Inc. (20 Park Plaza, Suite 1014, Boston, Massachusetts 02116). Additional references: http://www.mcw.edu/midas/health/SF-36.html and http://www.nationalmssociety.org/MUCS_health.asp.

- ***Kurtzke Functional System Scores (FSS) and Expanded Disability Status Scale (EDSS):*** The FSS and EDSS constitute one of the oldest and probably the most widely utilized assessment instruments in MS. Based on a standard neurological examination, the 7 functional systems (plus "other") are rated. These ratings are then used in conjunction with observations and information concerning gait and use of assistive devices to rate the EDSS. Each of the FSS is an ordinal clinical rating scale ranging from 0 to 5 or 6. The EDSS is an ordinal clinical rating scale ranging from 0 (normal neurologic examination) to 10 (death due to MS) in half-point increments. These may be found at www.nationalmssociety.org/MUCS_FSS.asp.

- ***Minimal Assessment of Cognitive Function in MS (MACFIMS):*** An expert panel convened by the Consortium of MS Centers in 2001 developed this neuropsychological assessment for patients with MS. This is a 90-minute battery of 7 neuropsychological tests covering processing speed/working memory, learning and memory, executive function, visual-spatial processing and word retrieval. Reference: Benedict R. et al. "Minimal neuropsychological assessment of MS patients: A consensus approach." *Clin Neuropsychol* Aug 2002; 16(3): 381–397.

- ***Modified Fatigue Impact Scale (MFIS):*** Consists of 21 items to determine the effects of fatigue in terms of cognitive, physical, and psychosocial functioning. An abbreviated version consists of 5 items. The MFIS is part of the MSQLI and can be downloaded in PDF format from www.nationalmssociety.org/MUCS_fatigue.asp.

- ***MS Functional Composite (MSFC):*** Includes the Timed 25-foot walk (T25-FW), 9-hole peg test (9HPT), and the Paced Auditory Serial Addition Test (PASAT): The MSFC Administration and Scoring Manual can be downloaded in PDF format from the National MS Society website www.nationalmssociety.org/MUCS_MSFC.asp.

- ***MS Quality of Life-54 (MSQOL-54):*** A multidimensional health-related quality of life measure that combines the SF-36 and 18 items that are MS-specific including fatigue and cognitive function. It can be downloaded in PDF format from www.nationalmssociety.org/MUCS_MSQOL-54.asp.

- ***MS Quality of Life Inventory (MSQLI):*** A structured self report encompassing the following components: SF-36, Modified Fatigue Impact Scale, Pain Effects Scale (PES), Sexual Satisfaction Scale (SSS), Bladder Control Scale (BLCS), Bowel Control Scale (BWCS), Impact of Visual Impairment Scale (IVIS), Perceived Deficits Questionnaire (PDQ), Mental Health Inventory (MHI), Modified Social Support Survey (MSSS). The MSQLI: A User's Manual can be downloaded as a PDF file from www.nationalmssociety.org/MUCS_MSQLI.asp.

- ***Occupational Performance History Interview:*** A semi-structured interview that explores the client's life history in the areas of work, play, and self-care performance. Available from the Model of Human Occupation Clearinghouse: www.moho.uic.edu/assessments.html.

- ***Range of Motion (ROM) and Manual Muscle Test (MMT) and Grasp Dynamometry:*** Range of motion at selected joints is assessed using a goniometer that measures the angle of the joint through its range. Manual Muscle testing uses a 6 point grading system (0 = no contractile ability; 5 = strength through full ROM with maximum resistance) to assess strength where the patient has selective joint control. Grasp Dynamometer Testing uses a dynamometer to measure grasp and pinch strength in pounds.

- ***Tinetti Assessment Tool:*** Easily administered test that measures gait and balance. The test is scored on a three-point scale to assess the patient's ability to perform specific tasks. Scores are combined to form three measures—an overall gait assessment score, an overall balance assessment score, and a gait and balance score. The scores can be interpreted with regard to risk for falls. Reference: Lewis C. "Balance, gait test proves simple yet useful." *PT Bulletin* 1993; 2/10: 9, 40. Also, Tinetti M.E. "Performance-oriented assessment of mobility problems in elderly patients." *JAGS* 1986; 34: 119–126.

LEISURE ACTIVITY BATTERIES

- ***Idyll Arbor Leisure Battery*** (Idyll Arbor, 39129 264th Ave SE, Enumclaw, WA 98022; phone: 360-825-7797; fax: 360-825-5670): Available in Spanish. Consists of several subscales:

  a. The ***Leisure Attitude Measurement*** measures the individual's attitude toward leisure on three different levels: (1) cognitive, (2) affective, and (3) behavioral. It can be used to find areas that are preventing the individual from participating actively in leisure. Limited normative data is available.

  b. The ***Leisure Interest Measurement*** helps identify the degree to which an individual is interested in each of the eight domains of leisure activities: (1) physical, (2) outdoor, (3) mechanical, (4) artistic, (5) service, (6) social, (7) cultural, and (8) reading. It can be used to make sure that the individual has activities available which are interesting to him/her and to point out areas where the therapist can provide education to make more domains of activity interesting.

  c. The ***Leisure Motivation Scale*** measures an individual's motivation for participating in leisure activities. The four primary motivators identified by research are (1) intellectual (the extent to which the individual is motivated to engage in leisure activities that involve mental activities such as learning, exploring, discovering, creating, or imagining), (2) social (the extent to which an individual engages in leisure activities because of the need for friendship and interpersonal relationships and the need to be valued by others), (3) competence-mastery (the extent to which the individual engages in leisure activities in order to achieve, master, challenge, and compete), and (4) stimulus-avoidance (the extent that an individual needs to escape and get away from over-stimulating life situations). It is useful for establishing the components of leisure activities that motivate the individual to participate.

  d. The ***Leisure Satisfaction Measure*** indicates the degree to which an individual feels his/her general "needs" are being satisfied through leisure. The six subscales of satisfaction are (1) psychological, (2) educational, (3) social, (4) relaxation, (5) physiological, and (6) aesthetic. It is useful for establishing that an individual's needs for leisure are being met by the existing programs and for finding areas where interventions may increase the individual's level of satisfaction with leisure.

- ***Leisure Assessment Inventory*** (Idyll Arbor, 39129 264th Ave SE, Enumclaw, WA 98022; phone: 360-825-7797; fax: 360-825-5670): The Leisure Assessment Inventory was originally developed at Indiana University Center on Aging and Aged, Bloomington, IN. The authors of the Leisure Assessment Inventory in 1997 are Barbara A. Hawkins, Re.D.; Patricia Ardovino, Ph.D., CTRS; Nancy Brattain Rogers, Ph.D.; Alice Foose, MA; and Nils Ohlsen. The Leisure Assessment Inventory (LAI), measures the leisure behavior of adults through four components.

  a. The ***Leisure Activity Participation*** (LAP) index reflects the status of a person's leisure repertoire; thus, it presents a measure of activity involvement. The LAP

evaluates the individual's current leisure functioning as determined by a set of pictures of activities that are typical of adult leisure.

b. The ***Leisure Preference Index*** (L-PREF) provides a measure of leisure activities in which the individual would like to increase participation. This index indicates a degree of preference for some activities over other activities.

c. The ***Leisure Interest Index*** (L-INT) measures the degree of unmet leisure involvement based on the selection of activities in which the individual has an interest, but in which he or she is not participating or is prevented from participating.

d. The ***Leisure Constraints Index*** (L-CON) of the LAI assesses the degree of internal and external constraints that inhibit participation in leisure activities.

APPENDIX
B

Specialized MS Adult Day Programs

Some adult day programs target individuals with multiple sclerosis and provide specialized programming to meet the needs of this population. Special considerations involved in this kind of programming include the following:

- Transportation that can accommodate large, power operated wheelchairs.
- Space requirements, especially if participants use power wheelchairs; need for rehabilitation/exercise space, rest areas, showers, etc.
- Funding: For those with high intensity needs, public funding frequently does not cover actual costs.
- Staffing: Ratios may need to be higher than in a traditional program and there may be a need for more skilled staff, e.g., rehabilitation professionals.
- Rehabilitation: This component of the program is an important feature for participants and is not generally provided/funded on site in most adult day programs.
- Greater need for medical/nursing services, e.g., injectable MS medications.
- Competency issues for participants with MS: Cognitive impairments can interfere with ability to participate fully and may often be subtle.
- Discharge criteria/increased acuity: When participant's needs exceed the ability of program to meet those needs
- Need for family support/respite: Support and education programs for family members to enhance the family's coping ability and avoid premature institutionalization.

Following are brief descriptions of several specialized MS adult day programs. Contact the staff of these programs if you would like more information about developing specializd MS programming at your center.

MELLEN DAY TREATMENT CENTER (CLEVELAND)

This program meets once a week for most of the day. Lunch is provided free of charge. Participants plan and make visits to museums, community performances and shopping centers. The program is open to individuals who are 20 to 65 years of age who have been diagnosed with MS and have limited ability to perform activities typical to their daily routines.

This program is designed to help participants adapt to their disabilities, meet and spend time with others who have MS, and provide respite for family members who are caring for someone with MS. Participants undergo a series of evaluations to assess their treatment needs and goals before entering the program. Services include:

- Occupational therapy: Gain skills for managing daily tasks and for maintaining independence and self-control
- Physical therapy: Take part in activities to help reach full physical potential.
- Nursing: Learn how to identify and manage MS symptoms and avoid complications.
- Psychology: Learn ways of coping with MS difficulties.
- Social work: Learn ways to build and strengthen one's support network.

Contact the Mellen Center at 216-444-8600.

FAIRVIEW MS ACHIEVEMENT CENTER (MINNEAPOLIS)

The Fairview MS Achievement Center operates Monday through Friday. Individuals with MS participate in the program one day per week from 10:00 a.m. to 3:20 p.m. A variety of activities and services are offered, including:

- Recreation: Wheelchair aerobics (adapted activities such as painting, woodworking and ceramics, music, educational programs and speakers.
- Counseling: Support and issue groups.
- Wound prevention program.
- Health and wellness: Nutrition, relaxation and stress management education.
- Opportunities to socialize.
- Caregiver support groups.
- Physical therapy: Stretching, range-of-motion; aerobic activities, gait (walking) training, flexibility, balance and coordination exercises and seating and positioning services.

- Occupational therapy: Compensation techniques for both physical and cognitive (thinking) problems, energy conservation techniques, strengthening methods, building tolerance for activity and improving their ability to perform activities of daily life.
- Social workers to help participants arrange the most efficient, least expensive form of transportation to and from the center.

The goal of the program is to help people with MS remain as active and independent as possible so they may remain in their homes, and to provide family members and caregivers with respite, support and resources.

Contact the Fairview MS Achievement Center at 612-672-2815.

MS ACHIEVEMENT CENTER, UNITY HEALTH SYSTEM (ROCHESTER, NY)

This program operates Monday to Friday, 8 a.m. to 5 p.m., and is open to anyone who lives in Rochester or surrounding counties, with a diagnosis of MS or other neurological disorder.

The MS Achievement Center is a collaborative program of Unity Health System and the National Multiple Sclerosis Society—Upstate NY Chapter. This program serves mid- to late-stage MS patients, as well as individuals with other neurological diagnoses. The average age of registrants is 40 to 50 years old.

Services provided are:

- Full range of on-site nursing services.
- Daily exercise programs.
- Social work and case management services.
- Hot, nutritious meals.
- Recreation and socialization programs and activities.
- Medication administration.
- Counseling and support groups.
- Assistance with transportation arrangements.

For more information about the MS Achievement Center, please call 585-368-6470.

KING ADULT DAY ENRICHMENT PROGRAM (DENVER)

Located on the Marycrest Campus, KADEP is open Monday through Friday from 7:30 a.m. to 4:30 p.m. Each day, participants can select from among 7 to 10 classes and activities. Activities include hydrotherapy (water exercise), hippotherapy (equestrian therapy), golf, bowling, fine arts and craft classes. Breakfast and lunch are provided daily. Wellness monitoring and assistance with physical needs are always available

The King Adult Enrichment Program (KADEP) is a program specifically designed to meet the needs and interests of younger adults with neurological illnesses and disabilities. The program seeks to enhance quality of life by picking up where traditional health care leaves off, providing day to day support in living with the changes disability brings. KADEP provides opportunities for participants to explore and enjoy a wide variety of life-enriching recreational and social activities, addressing each individual's needs, interests and abilities.

For further information about any aspect of the program, please call 303-433-6887.

MARILYN HILTON MS ACHIEVEMENT CENTER (LOS ANGELES, CA)

The Marilyn Hilton MS Achievement Center at UCLA is a collaborative program offered by the UCLA Department of Neurology and the Southern California Chapter of the National Multiple Sclerosis Society. This day program operates Tuesday to Friday, 10:00 a.m. to 3:00 p.m. Onsite intake evaluation is required. The fee is $75 per day. Sliding fee scale scholarships are available. The philosophy of the Center is that people with MS can be empowered to take control of their health and well-being with the help of educational and experiential programs.

Participants or "members" come one day per week, and upon enrollment commit to regular attendance and a minimum of 6 months in the program. During the program day members rotate between large group, small group, and 1:1 wellness activities covering many aspects of wellness.

- Physical wellness: A customized physical activity program that may include yoga, tai chi, and exercises in the fitness center.
- Emotional wellness: Support groups and art therapy groups.
- Recreation wellness: Activities such as adaptive gardening, adaptive computing, cognitive stimulation, animal assisted therapy, music therapy, and journaling.
- Health education: Information regarding disease management, symptom management, and general health practices.

The program is designed to help people meet their own wellness goals, and can include the following outcomes:

- Improve or maintain functional abilities.
- Increase or maintain mobility.
- Reduce stress and improve emotional status.
- Increase self-esteem and decrease isolation.
- Prevention of secondary medical complications.

Contact the center at 310-276-4071.

MID-AMERICA ACHIEVEMENT CENTER (KANSAS CITY, MISSOURI)

This center is a one-day-a-week clinic where participants receive one hour each of physical therapy, occupational therapy, recreational therapy and participation in a psychologist-facilitated support group. In addition, a speech therapist and a nurse are available to address swallowing problems, bladder and bowel function, skin care, and other health issues.

Services are funded by the Achievement Center and by the participants, who pay a monthly fee. Activities include gait and mobility training, exercise, balance training, energy conservation, and group and individual counseling.

For more information contact 816-751-7777.

MS WELLNESS PROGRAM AT GOOD SHEPHERD (PHILADELPHIA)

This MS Wellness Program is sponsored by the Good Shepherd Neurorehabilitation Center of Excellence in partnership with the Greater Delaware Valley Chapter of the National Multiple Sclerosis Society. The program operates Tuesday and Thursday, four hours each day. Applications are accepted on an on-going basis. Entrance criteria are used to admit appropriate applicants. The fee is $35 per session and financial assistance is offered to anyone in need through a sliding scale fee schedule. Participants come one or two days per week, and those with significant disability are asked to provide an aide to assist them during the program. Participants receive group and one-on-one wellness interventions including gentle yoga, cognitive exercises, community outings, creative and expressive art groups, and education on various disease and lifestyle topics.

Contact the Center at 610-776-9303.

APPENDIX
C

Resources

THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

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

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

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

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

Programs Offered by the NMSS

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

- ***Comprehensive information and referral programs:*** Each chapter maintains a database of resources and information pertaining to all aspects of multiple sclerosis and services available in the community to meet the many needs generated by the disease.
- ***Education:*** Chapters offer programs on all aspects of MS for people with MS, family caregivers, and health care professionals. Programs for people with MS and families emphasize the value of self-advocacy and empowerment in directing their MS care.
- ***Self-help groups and counseling programs:*** These are offered to help people with MS and families cope with the day-to-day challenges of living with the emotional demands of this chronic, unpredictable and often disabling disease. There are over 2000 Society-affiliated support groups across the United States.
- ***Caregiver supports:*** The Society recognizes that informal caregivers—unpaid family, friends, and neighbors—provide the majority of long-term care. Educational and support programs are offered by many chapters to help caregivers attend to their own emotional needs as well as learn how to best care and advocate for their loved one with MS.
- ***Family programs:*** The Society offers a variety of programs that bring families together for education, emotional support, and/or social activities. These programs are offered in recognition of the fact that MS affects each member of the family uniquely and generates different needs for each.
- ***Advocacy:*** The Society is a preeminent voice for people with disabilities who require access to the range of affordable, quality, and age-appropriate long-term care services. Through our chapters and national government affairs office in Washington DC, our advocates have a say in such long-term care issues as the Medicare and Medicaid programs, policies regulating nursing home care, assisted living, independent living programs, insurance and more on a federal, state, and local level.
- ***Research:*** The Society supports a wide range of clinical and scientific research in MS. In addition, research in health services and policy provides data to support our advocacy work and helps identify and document the unique long-term care and health management needs of our constituents.
- ***Specific long-term care programs:*** Many of our chapters collaborate with long-term care providers to develop and offer specialized long-term care programs for people with MS in their communities. For example, several specialized MS adult day care

programs and specialized MS nursing home programs are offered across the country. A number of MS care management programs, respite care programs and MS assisted living programs have also been developed.

To reach your NMSS chapter call 1-800-FIGHT MS.

Collaboration with Local NMSS Chapters

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

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

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

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

LEISURE INTERESTS/ACTIVITY RESOURCES

- Accessible Gardening; Woodbine House Publisher. 1-800-843-7323
- Community Recreation for People with Disabilities; Paul Brooks Publishing. 1-800-638-3775
- Don’t Forget the Fun; Institute for Community Inclusion. 617-355-6506

- A Guide to Wheelchair Sports and Recreation; Paralyzed Veterans Association. 602-224-0500
- Introduction to Fitness with Persons Who Are Disabled; Vinland National Center. 612-479-3555
- Access to Recreation (catalog). 1-800-634-4351
- Recreation Therapy Consultants ('Activity Care Planning Cookbook' and 'The Psychosocial Care Planning Almanac'). 858-546-9003
- National Senior Games Association. 225-766-6800
- World Wide Games. 1-800-888-0987
- *A Practical Guide to Art Therapy Games* by Diane Fausek
- American Association for Active Lifestyles and Fitness. www.aahperd.org/aaalf
- National Association of Activity Professionals. www.thenaap.com
- National Certification Council for Activity Professionals. www.nccap.org
- National Library Service for the Blind and Physically Handicapped. 1-800-424-9100
- American Horticultural Society. www.ahta.org
- Therapeutic Recreation Directory. http://www.recreationtherapy.com/rt.htm
- American Therapeutic Recreation Association. http://www.recreationtherapy.com/rt.htm
- *Activity Director's Guide* (magazine). www.care4elders.com

RESOURCES ABOUT MS AND DISABILITY

Organizations

- National Multiple Sclerosis Society: A resource for individuals with MS, their families, and professionals caring for individuals with MS. It includes information about research, publications, and numerous areas of interest. www.nationalmssociety.org
- The Professional Resources Center: This center provides information and multi-disciplinary expertise about MS and its management to health care professionals; it is supported by the National MS Society. www.nationalmssociety.org/prc.asp
- International Organization of MS Nurses: A professional organization of MS nurses that educate and facilitate communication about MS and current MS research to the healthcare community. www.iomsn.org

- Consortium of MS Centers (CMSC): A professional organization for MS healthcare providers and researchers to improve the quality of life of people affected by MS. www.mscare.org/
- National Adult Day Services Association: An organization representing Adult Day Services providers. A resource for any provider of Adult Day Services. www.nadsa.org
- State Adult Day Services Associations: Many states have their own state Adult Day Services Association. Contact information for state associations can be found on the NADSA website. www.nadsa.org/links/stateassociations.htm
- Health Resource Center for Women with Disabilities: The center is a project run by and for women with disabilities. It provides a free newsletter, support groups, educational resources (including a video on mothering with a disability), and educational seminars addressing issues from a disabled woman's perspective. www.rehabchicago.org
- National Association for Continence: Consumer advocacy organization dedicated to public education regarding causes, prevention and management of incontinence. www.nafc.org
- National Council on Disability (NCD): The Council is an independent federal agency whose role is to study and make recommendations about public policy for people with disabilities; it also publishes a free newsletter. www.ncd.gov
- National Family Caregivers Association (NFCA): The organization is dedicated to improving the quality of life of America's caregivers. It publishes a newsletter, has a resource guide, an information clearinghouse and a toll-free hotline. www.nfcacares.org
- Well Spouse Foundation: The organization provides a support network for people married to or living with a chronically ill partner, as well as advocacy and a newsletter. www.wellspouse.org
- Through The Looking Glass (TLG): TLG is a disability community-based non-profit organization that provides national research, training, and services for families of adults with disabilities. www.lookingglass.org

Videos for Staff Training

- "But You Look So Well": The emotional, social, and concrete impact of MS on the lives of four individuals and their families. Participants share their stories of living and striving to cope on a daily basis with this difficult illness. Also, a prominent neurologist provides information on the disorder and shares his views on how people can learn to live their lives with MS. www.aquariusproductions.com
- "From Rules to Caring Practices": Training package which addresses ethical issues faced by frontline homecare and adult daycare workers. www.fanlight.com

- "Hello in There": Captures the rewards and challenges of 'person-centered' care, relating to participants as whole people, with histories and values that go beyond their current medical needs. www.fanlight.com
- "My Body Is Not Who I Am": Introduces viewers to people who openly discuss the struggles and triumphs they have experienced living in a body that is physically disabled. They talk honestly about the social stigma of their disability and the problems they face in terms of mobility, health care, and family relationships, as well as the challenges of emotional and sexual intimacy. www.aquariusproductions.com
- "Not on the Sidelines": Profiles four people whose lives were suddenly changed by injury or illness when they were teens or young adults. It discusses how they challenged their disabilities to create new, active, and rewarding lives. www.fanlight.com
- "Video Guide to (Dis) Ability Awareness": An orientation to the Americans with Disability Act (ADA), with helpful and practical suggestions for compliance. www.fanlight.com
- "Promoting Quality Care for People with MS: A Training Video for Aides": Addresses issues identified by people with MS and their aides as having the most impact on the delivery of appropriate and sensitive care. www.nationalmssociety.org

Accessibility, Assistive Technology, & Environmental Design

- Abledata: A federally funded source for information on assistive technology and rehabilitation equipment sponsored by the National Institute on Disability & Rehabilitation Research, US Department of Education. www.abledata.com
- Access Board: An Independent federal agency devoted to accessibility for people with disabilities. They develop and maintain accessibility requirements and provide technical assistance & training on these guidelines and standards. www.access-board.gov
- Alliance For Technology Access: A network of community-based resource centers, developers, vendors and associates who provide information and support services to people with disabilities and help them to increase their use of standard, assistive, and information technologies. www.ataccess.org
- Americans with Disabilities Act (ADA) Guidelines: Accessibility guidelines and standards for the ADA as well as the Architectural Barriers Act (ABA) and the Uniform Federal Accessibility Standards (UFAS). www.access-board.gov
- Assistivetech.net: A site created by Georgia Tech Center for Assistive Technology & Environmental Access (CATEA) to serve as a resource for assistive technology. www.assistivetech.net

- Center for Assistive Technology & Environmental Access (CATEA): A center within the Georgia College of Architecture, Institute of Technology, whose core mission is the development, evaluation, and utilization of assistive technology and the b and development of accessible environments. www.catea.org
- Center For Universal Design: A national research, information, and technical assistance center that evaluates, develops, and promotes universal design of products and environments to be useable by as many people as possible at little or no extra cost. www.ncsu.edu/ncsu/design/cud/
- Disability Info.gov: A central governmental website for information relating to accessibility and assistive technology resources and programs. www.disability-info.gov
- "Going to the Source for Accessibility Assessment": An article by Phyllis Cangemi, Wayne Williams, and Paul Gaskill on how to make outdoors/nature accessible. www.wholeaccess.org
- National Center On Accessibility: A collaborative program of Indiana University and the National Park Service focusing on creating and providing technical assistance for inclusive recreational opportunities for people of all abilities. www.ncaonline.org
- New Horizons Unlimited: A non-profit organization whose mission is to make information and life experiences accessible to individuals with lifelong disabilities and their families. www.new-horizons.org
- Paralyzed Veterans of America (PVA): Their architecture program promotes accessible design through technical assistance services, standards development, design guides, and building-code initiatives. www.pva.org
- Tech Connections: A resource for information on assistive technology to accommodate people with disabilities in the workplace and in everyday life activities. www.techconnections.org/
- USA Tech Guide: A web guide to wheelchair and assistive technology choices and wheelchair reviews. www.usatechguide.org
- Rehabilitation Engineering and Assistive Technology Society of North America: www.RESNA.org

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