

Assessment

Home health staff and personal care assistants have regular contact with the client and his/her family and are thus able to observe changes in functional and medical status over time. Here are various domains of health that should be assessed periodically. When you notice a change, bring it to the attention of the home health team leader or the client's physician. Change in these domains may signal progression of the disease, the beginning of a relapse, an infection or other medical or mental health problem.

Domains of Health That Should Be Assessed Periodically

Domain	What to Assess
Mobility	<p>Transfers, walking, wheelchair mobility, bed mobility, balance</p> <p>Has there been a change in:</p> <ul style="list-style-type: none"> ■ the client's ability to move about the room? ■ his/her ability to transfer in and out of bed, to the wheelchair, to the toilet, shower, car, etc.? ■ his/her ability to turn and come to a sitting position while in bed? <p>What appears to be contributing to the change?</p> <ul style="list-style-type: none"> ■ Weakness? ■ Spasticity? ■ Poor balance? ■ Fatigue?
Functional Independence	<p>Dressing, grooming, feeding, bathing, personal hygiene.</p> <ul style="list-style-type: none"> ■ Is the client less/more independent in accomplishing ADLs? ■ What appears to be causing the change in status? ■ Does he/she appear to need assistive devices or more personal help?
Vision/Hearing	<ul style="list-style-type: none"> ■ Has there been a change in visual acuity? visual field? ■ Is the client experiencing double vision? ■ Is there a change in hearing?
Speech	<ul style="list-style-type: none"> ■ Is there a change in the client's ability to speak and be understood? ■ Does speech sound slurred? ■ Is there low volume?
Skin Integrity/ Sensation	<ul style="list-style-type: none"> ■ Are there any reddened areas on the skin? ■ Are there any areas of skin breakdown? ■ Is there an increased number of bruises? ■ Is there a change in sensation: numbness? burning, banding, itching or other uncomfortable sensations?

Domains of Health That Should Be Assessed Periodically (*continued*)

Domain	What to Assess
Bladder/Bowel Functioning	<ul style="list-style-type: none"> ■ Is there a change in bladder function? ■ Is there increased frequency and/or urgency of urination? ■ Is the client having more accidents? ■ Is there a change in bowel function? ■ Is there a change in frequency of bowel movements, constipation, diarrhea? Bowel accidents?
Cognition	<ul style="list-style-type: none"> ■ Is there a change in the client's ability to concentrate, remember things, organize his/her thoughts, make sound judgments?
Pain	<ul style="list-style-type: none"> ■ Does the client report increase in pain? ■ What is the nature of the pain? ■ Where does he/she experience it? ■ When?
Depression/ Emotional Status	<ul style="list-style-type: none"> ■ Does the client appear depressed? ■ Is he/she expressing sadness, crying, withdrawal? ■ Does he/she seem inappropriately euphoric? ■ Are there frequent mood changes? ■ Does the client appear anxious or worried? ■ Does the client experience uncontrolled laughing or crying?
Nutritional Status/ Swallowing	<ul style="list-style-type: none"> ■ Are there changes in the client's appetite and interest in food? ■ Is the client able to swallow without choking? ■ Is he/she getting adequate hydration and nutrition?

Primary Healthcare Needs

Issues that relate to good general health and wellness are often neglected in persons with MS. Symptoms that may stem from a non-MS cause are often assumed to be another symptom related to MS. Health concerns of relatively young persons receiving home care 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.

If you can, help individuals to identify accessible healthcare providers in the area and encourage regular medical check-ups. People with MS should adhere to the health-screening schedule recommended for all adults:

- Pap testing for women of reproductive age
- Clinical breast or testicular examination after age 20–25
- Annual mammogram for women after age 40–50 years
- Fecal occult blood testing and colonoscopy for men and women who are over 50 or have other risk factors
- Serum screening for dyslipidemia and thyroid abnormalities
- Bone densitometry (such as dual energy X-ray absorptiometry or DEXA) for anyone at risk for fractures or osteoporosis (particularly those with a family history and/or reduced mobility)
- Cholesterol once under age 50 and every 5 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

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, or inability to stand 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. Some medical offices are outfitted with accessible exam tables that provide ease in transferring from a wheelchair and positioning for individuals with mobility impairments. Family members should be supported in helping their family member with MS seek out institutions and providers that can meet their accessibility needs.

When providing care to 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. Menstrual cycles may be altered by medications such as steroids, chemotherapy and others that may be used to treat MS.

Menopause: In women with MS, as with other women, menopause can cause uncomfortable symptoms, such as hot flashes, vaginal dryness, sleep disturbance, and mood changes. Some may consider hormone replacement therapy. However, there are serious risks as well as benefits of hormone replacement therapy that should be addressed by the person with MS and the physician. Thrombo-embolic risk, particularly that of deep vein thrombosis, is especially relevant in the person with MS who has mobility problems and may tend to be sedentary, particularly if they are overweight. Hormone replacement therapy should be avoided in such individuals, as well as in persons with a strong family history of cancer of the breast, ovarian or uterine cancers, cerebrovascular disease, and coronary artery disease.

Deep Vein Thrombosis (DVT): With regard to the risk of deep vein thrombosis and its particularly dangerous complication, pulmonary embolus, the person with MS who is immobile and/or tends to be sedentary, particularly if he or she is overweight, should consider with their physician whether or not to be anti-coagulated and if so, which anticoagulant is appropriate. The individual should discuss risks and benefits of such therapy with the physician.

Heat and Humidity: People with MS can be extremely heat sensitive. This is traditionally a very common problem in the MS population. Those with heat sensitivity may notice an increase in their MS symptoms including fatigue, visual disturbance, balance, and diminished strength when their body temperature rises. Cooling will likely restore a prior level of functioning but may take some time. People with MS may find that spasticity worsens with cold.

TIPS: Heat and Humidity

1. Keep the environmental controls at an even temperature.
2. Put fans in the areas where exercise is performed.
3. In the summer, encourage the use of cold packs, cooling vests, or cool cloths on the neck, back, or head.
4. In the summer, encourage iced drinks or “slurpees”.
5. When outdoors, limit the time in the heat, make sure shaded areas are available, and make sure the car/van is comfortable before entering the vehicle.
6. Encourage individuals to work with their physicians for appropriate changes in anti-spasmodics in the winter.
7. Air conditioners should be considered a medical necessity.

Osteoporosis: All individuals with multiple sclerosis should be considered at risk for osteoporosis. Not infrequent use of steroids and reduced physical activity promote osteoporosis in both men and women with multiple sclerosis. Treatment and prevention with calcium rich foods and dietary supplements (including calcium and 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 those with reduced bone density. Regular bone density testing 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 beverages or taking a cold bath or shower after exercising) can alleviate these changes, caused by the temporary elevation in core body temperature. Avoid being over-zealous in exercise programs. Activities such as Yoga and aquatherapy (in cool water) are particularly popular with people with MS. Exercise should target both MS impairments and generalized fitness. Supervision by a physical therapist is often of benefit.

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 by raising body temperature. This type of pseudo-exacerbation will subside as the fever subsides. As a corollary, worsening of symptoms may herald fever and/or infection. With the worsening of symptoms, temperature should be ascertained and infections, particularly respiratory and urinary tract, ruled out and, if present, treated in a timely fashion. Symptoms that occur in the presence of a fever should be carefully assessed to determine whether they are indicative of a true attack that should be treated.

Hypothyroidism: This condition can cause slowing down, fatigue, weight gain, slowed thinking, and even neurologic symptoms that may be confused with MS symptoms. Referral to the family doctor or neurologist of the person with MS should be made if there is an unexplained worsening of symptoms.

Arthritis and Musculoskeletal Pain: The aches and pains of arthritis and muscle strain and/or sprain are often ascribed to MS, since about half of people with MS have nonspecific pain. It is very important that assessment of pain consider non-MS causes.

Sleep Disturbance: Disruption of sleep is common in the MS population and can worsen daytime fatigue. Frequent nighttime waking may be the result of muscle spasms, urinary frequency, pain, depression, and sleep disorders such as restless leg syndrome and sleep apnea. Such disturbances should be considered in order to determine specific contributing factors so that treatment might be appropriately designed. Specific sleep disorders might relate to hypersomnia and fatigue and also worsen cognitive dysfunction.

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, weight should be monitored and a diet that meets nutritional needs and prevents serious weight gain should be maintained. Obesity makes for risk in terms of thrombo-embolic disease, diabetes, and other disorders. Consultation with a nutritionist may be indicated.

Immunizations: Recent studies have not demonstrated that influenza vaccination causes MS attacks or accelerates progression of the disease. Having MS should not preclude an individual from having a flu shot. The flu can be a very serious illness, particularly in a person with MS who has compromised respiration, and the high fever accompanying influenza may exacerbate MS symptoms. The flu, a viral illness, may be associated with an MS relapse, usually after a latent period. Altogether then, it appears that it is safer to have an influenza vaccination rather than to avoid one, but the decision as to whether or not to vaccinate should be made on an individual basis in consultation with the physician taking into consideration all health risks of both receiving and avoiding flu vaccination.

Pneumonia: Pneumonia in sedentary persons with MS is not uncommon. Weakness of respiratory muscles predisposes individuals to pneumonia that is more difficult to treat. When you notice an individual choking or having swallowing difficulties a referral for a swallowing evaluation is appropriate. Recommendations from that evaluation should be followed to prevent aspiration that can contribute to pneumonia, especially for someone with a suppressed immune system and/or who is severely impaired. Pneumococcal vaccination (Pneumovax) should be done once every five years.

Respiratory Status: An assessment of respiratory status in the very impaired should include observation of respiratory and pulse rates, effectiveness of ventilation, ability to clear secretions, changes in speech pattern, shortness of breath, restlessness, confusion, and change in skin color. A respiratory care plan might include the following:

- Proper positioning. If an individual slumps, they will restrict ventilation. A safety belt should be tied loosely around the body. When the individual is resting or sleeping, the head of the bed might be elevated, 15–30 degrees to assist in ventilation.
- The individual should be encouraged to cough and deep breathe at least once every four hours. An incentive spirometer might be used to encourage an individual to reach a goal with deep breathing. Because an individual with MS might have an insufficient cough to clear secretions spontaneously, postural drainage of secretions should be taught to the individual with MS and their caregivers when muscles of respiration and or cough are limited.
- Suctioning can be used to clear the oral pharynx of secretions. An individual with MS can be taught how to suction himself orally to prevent drooling.
- With severely impaired individuals, respiratory complications are frequently life threatening. The individual, family, and physician, must openly discuss to what extent life support measures will be used. Although these discussions are very difficult and painful for all concerned, they are better discussed before life threatening complications occur. With acute reversible respiratory illnesses, sometimes temporary intubation and mechanical ventilation might be necessary until respiratory muscle strength returns and infection is treated. Early detection of respiratory complications, especially infection and pulmonary embolus, must be emphasized. The individual with advanced MS, his family, other caregivers and homecare team members must show familiarity and comfort with procedures to maintain respiratory care.

Daily Care Issues

Many individuals with MS depend on assistance for their activities of daily living. The type and degree of help needed will vary from client to client and may vary even from time to time for the same individual. Some individuals may be able to perform some tasks or parts of tasks and require help with limited aspects of care. Others will require full assistance. Others may be physically able to perform a task, but the energy expenditure is not practical. Still others may be able to perform tasks independently one day but not the next. While home health staff are trained to assist clients with various diagnoses and functional limitations, below we highlight issues that may be unique to assisting home health clients with MS.

Bathing/Showering: A younger client may prefer showers more frequently than a geriatric client. Transfers to the tub or shower may be challenging, depending on the layout of the bathroom and assistive devices available. Since the bathroom is a frequent location for falls, discuss the best techniques the client has developed to safely transfer and the equipment he/she uses (e.g., transfer board, shower bench or chair, hand-held shower, grab bars, soap-on-a-rope, etc.). Some clients may need to have a bath set up while in the bed or wheelchair if accessibility of the bathroom presents a problem.



Photos in this chapter courtesy of Greg Baird, Wesley Medical Supply, Glenside, PA

Bathroom Equipment: Individuals who have balance and movement deficits may require a transfer chair or bench to move into the tub/shower safely. Once inside, he/she may need to remain seated on the chair or bench while bathing or showering. The types of chairs that may be used are shown above.

If the individual has weakness in the legs, the use of a toilet riser can be very supportive to help prevent falls. At night, the use of a bedside commode can save walking to the bathroom and prevent falls. Commodes are particularly helpful if the bathroom is on a different floor, or if the bathroom is a long distance from where the individual spends most of his/her time.



If the person cannot stand independently, the care provider can use his/her feet and knees as a brace for their feet and knees. Place the chair at a 90-degree angle to the client with the strongest side leading the movement. Have the person lean forward and simply balance on his/her feet while turning one's body and the client's over the chair or commode. Bend from the knees to lower with them into the chair or onto the commode. If a person can't stand, another option is to use a slide board to assist in the transfer. If the person is paralyzed and cannot help at all with a transfer, it can be accomplished very safely using a mechanical lift.

Climate Control: Most people with MS experience heat intolerance. The individual's symptoms may temporarily worsen when he or she is exposed to any hot environment, such as a hot room, hot and humid weather, hot showers or bath, or if they develop a fever. If the client does not already have air-conditioning (or at a minimum, a fan), the home care worker should assist him/her in obtaining one. (The National MS Society chapter can often help with doing so.)

Dressing: As with all clients, personal choice in selecting clothing is important to self-esteem and independence. Some clients may use assistive devices such as reachers, or button hooks or adapted clothing such as Velcro closures, fasten-in-front clothing items, elastic waists, etc. As with all ADLs, allow the client to direct the care as much as possible.

Eating: Assistance may range from set up of adaptive devices to feeding the client. Some people with MS experience difficulty swallowing or chewing. A speech therapist and occupational therapist may be able to offer advice regarding positioning during eating, other swallowing and self feeding techniques, and adaptive equipment that might be useful for those with significant problems with this activity. Facilitate as much independence in eating as possible as self-feeding is often a priority for an individual as is a regular diet in spite of swallowing or chewing difficulties. Feeding should never be rushed. The client should concentrate on eating and swallowing and should not be distracted during meals or snacks to prevent choking or aspirating food. Eating should not occur if the client is sleepy or lethargic; the client should be alert, watchful, and upright. (See Dysphagia (Swallowing Difficulties), pages 18–19.)

Equipment and Assistive Technology: Power wheelchairs used by many persons with MS are often complex, with many features that may be new to the home care worker (e.g., tilt and recline devices, anti-tip devices, specialized control systems, etc.). Have the client and/caregiver explain the safe and appropriate use of these often expensive and vital items.

Do not recharge electric scooters or power wheelchairs while the client is sitting in them. In rare cases, these devices may catch fire during recharging. Recharge during waking hours and never while seated in the chair. The scooter or wheelchair must be turned off with the key removed while recharging. Recharge in an area where there is a smoke detector.

Some clients may have other equipment or devices to increase independence. Such devices as environmental control units (ECUs), which operate TVs, phones, stereos, door locks, etc. with voice control or manual switches, adapted computers, communication devices and others can improve quality of life for many individuals in their homes. However, it is important that the home care worker understand the correct use of these items so they can incorporate them into daily ADL routines, therapies and nursing care.

Exercise: Discuss the type of exercise program (e.g., range of motion, strengthening) and the equipment and positioning required. Appropriate exercise can increase fitness as well as minimize fatigue and deconditioning. Overall, exercise is good, however, the wrong exercises can generate injury and pain. A home exercise program ought to target both MS-related and non-MS issues. An exercise program ought to address cardiovascular fitness as well as strength and flexibility. A physical therapist should work with the client to develop a safe, appropriate program and should adjust it as necessary over time.

Grooming: Age-related ADLs may include shaving and leg waxing, or applying daily makeup in addition to other activities of daily living. These activities are important to self-esteem and may be seen more often in a younger population.

Instrumental Activities of Daily Living (IADLs): People with MS often require assistance with IADLs and homemaking staff may assist with laundry, housecleaning, meal preparation, grocery shopping, chores, shopping, and managing home finances. As with any client, it is optimal for the client to direct these activities as much as possible.

Scheduling: Flexible scheduling is appealing to younger clients and scheduling ADL tasks to avoid periods of fatigue may be beneficial. If possible, home care staff should work around the individual client's needs. Furthermore, many people with MS experience daily fluctuations of abilities so that need for assistance with activities of daily living may vary as MS fluctuates.

Socialization: Many people with MS and other physical disabilities may become isolated as a result of mobility problems, environmental barriers, fear and embarrassment related to bowel and bladder incontinence, depression and lack of ease socializing with others. Home care workers should encourage clients to contact the National MS Society chapter for information about social programs in the area and/or help with other services such as counseling, home adaptations, accessible transportation and other support that may alleviate this social isolation experienced by many individuals.

Toileting: As with all ADLs, the client (often in collaboration with his/her physical and occupational therapist) will have developed particular techniques that work with regard to transfers to the toilet or commode and management of personal hygiene. Younger women may still be menstruating and will require assistance with management of their periods. Discuss techniques with the client to determine the safest, most appropriate way to conduct these tasks. Some clients may have an established bowel routine that involves facilitating a bowel movement on a regular schedule. Many clients with MS use catheters and will require assistance with these devices. (See sections on Bladder and Bowel Dysfunction, pages 11–16.)

Transfers: Home health clients with MS often are heavier (they are younger and less frail) and because of MS spasticity, spasms, and paralysis, are usually more dependent in transfers than geriatric clients. Many may require use of lift devices (e.g., Hoyer lifts or home track lift systems) and other transfer aids (e.g., transfer belt, sliding board). Be aware of special considerations for transfers (e.g., shoulder pain, special techniques, protecting skin from friction or skin shear, etc.). Make sure the person has non-skid footwear on and that all moveable furniture and chairs are locked.



The lumber support brace is invaluable in helping to prevent back injuries of care providers. The person with MS should tell the home health provider what part of her/his body is weak or paralyzed. Make every effort to use the side/part that is strong during the movement. For example, if the right side is strong, the client should get out of bed on that side or move that side first so that it can pull the weaker side with it. If clients have symptoms of impaired balance and/or weakness, or if they are experiencing excessive fatigue, the use of a gait or transfer belt is very helpful. The client will feel more supported, and the care provider will be less likely to experience a back injury.

Lifts: Clients with lower and upper body weakness or paralysis may require complete assistance to transfer between bed, chair, and wheelchair. Mechanical lifts are one of the best assistive devices to use for this type of lift and movement. Most lifts have a sling that is placed under the person and then attached to the lift. They all roll and have a locking feature.

Lifts come in either manual or electric styles. If the client has a lift, proper use of the lift is necessary to avoid injury. Always review the manufacturer's instructions that come with the equipment before using it. Request an in-service by the medical supply company if additional instruction is required. Even better, have the client's occupational or physical therapist review the transfer technique with the home care worker and client together.

Body Mechanics: Body mechanics has been described as using the body in an efficient and safe way. Proper body mechanics requires good posture and the alignment of head, trunk, arms and legs over a good base of support where the feet are positioned about 12 inches apart. One should wear shoes with a non-skid surface on. General principles of movement and lifting are:

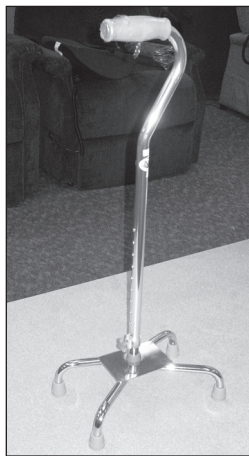
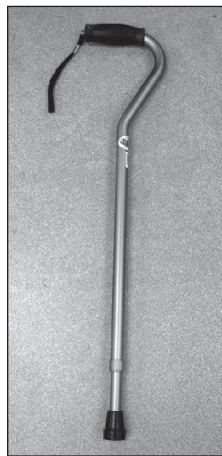
- Work in cooperation with the person.
- First determine what he/she can do and what help he/she needs.
- Explain each step and what he/she can do to help with the movement.
- Move together at the same time.
- Bend the knees and lift with the leg muscles, not the back muscles. Do not bend at the waist to lift an object.
- Exhale while lifting.
- Keep the person close to and in front of the body so as not to lean or bend at the waist.
- Turn the whole body rather than twist your back at the waist to complete a transfer.



- Push, pull or slide the person if you can, rather than lift.
- Transfer, rather than lift, if the person can help with the movement.
- Don't move people who are too heavy. Ask for help or get a mechanical lift.

Walking and Mobility: The client may use a cane or quad cane to help with balance, or he/she may use a rolling or non-rolling walker. Several new varieties of rolling walkers are available. One type walker that maximizes independence also has a seat if the client becomes tired; some have a container to hold personal items and purchases.

Clients may also use a scooter or wheelchair to increase mobility. Scooters are particularly helpful when weakness and fatigue are limiting a person's ability to walk distances. To use a scooter effectively, a person needs to be able to stand and transfer into the seat. Wheelchairs can either be manually driven, or powered by a battery. It is very important that a seating specialist prescribe the wheeled mobility for people with MS. Wheelchairs may also need to be fitted with additional padding to prevent skin breakdown. Falls and abrasions can occur with wheelchairs, so care should be taken to prevent these hazards.



Power Scooter



Manual Wheelchair



Power Wheelchair

Safety

The primary safety issues for clients with MS derive from mobility problems. Problems with mobility—weakness, coordination, balance, and spasticity—put an individual at an increased risk for falls and could potentially impede the ability to safely perform daily personal care tasks. Balance problems may pose safety risks, especially when coming to a standing position or transferring to or from a wheelchair. Complications of bowel and bladder dysfunction, especially when there is diarrhea, may generate an ambulatory safety issue given the nature of the emergency.

Diminished sensation may represent a safety concern, particularly regarding feeding (hot food and beverages), bathing (hot water), and smoking (burns). An individual with impaired sensory awareness may not feel pain that they might otherwise feel with normal sensation and be unaware of a need to reposition or a need for treatment for an area of skin breakdown.

Cognitive deficits and sensory deficits also place the client at risk for accidents. MS deficits that are not effectively managed may lead the individual to feel unsafe, develop fear and anxiety about leaving the home or engaging in any activities that are not routine. Furthermore, cognitive deficits may result in poor judgment, inattention, and disorganization that, particularly in the kitchen and bath, may place the individual at risk for injury. An individual's judgment, organizational and planning functioning may have impact on the safety of operating a power-operated wheelchair or scooter. There may be safety issues with regard to managing a manual wheelchair. The individual with cognitive impairment may not recognize an emergency situation and respond appropriately to it.

ADDRESSING SAFETY ISSUES

When going into the home of a new client for the initial visit, take special care to address safety issues:

- Look at safety regarding a client's ability to get in and out of the home. An occupational therapist or physical therapist can often help with this assessment.
- Discuss emergency preparedness.
- Consider what to do if the battery runs out for wheeled mobility.
- Identify if client lives alone or has caregiver at home or attendant.
- Plan safety access with each individual client.
- Consider questions like "What would you do if ...?" (Discuss possible scenarios together.)
- If there is smoking by the client, suggest a smoking vest that is fireproof.
- If available in the community, encourage your client to register with local fire and police re: special needs for evacuation.
- A "Vial of Life" can be placed in the refrigerator containing emergency information. The vial is used by emergency responders to quickly locate helpful information regarding medical history, medications, allergies and advance directives. A sticker is placed on the refrigerator alerting responders to the existence of the vial.



Proper transfer techniques and correct use of mobility aids will decrease risk. Adding to risk for falls is the home environment. An occupational therapist or home health nurse may be able to make recommendations for re-arrangement of furniture, removing small area rugs, installation of grab bars or use of other adaptive equipment to minimize this risk. Another way to maximize safety is having an easily accessible and usable phone (large buttons, hands-free dialing) or an Emergency Response System (ERS). Such a system usually consists of a call device on a bracelet or necklace. The device alerts an attendant who can summon necessary emergency responders.



Adjustable heat and air conditioning are necessary to avoid accidents relating to increased weakness and other symptoms generated by an increase in core body temperature and to an increase in spasticity generated by cold.

DEVELOPING AN EMERGENCY PLAN

Home care workers can assist individuals with multiple sclerosis, whether they live independently or with others, to prepare and be ready for emergencies.

- Assist the individual to complete a personal assessment of what kind of help they would need in an emergency. (For example: Would he/she be able to evacuate the home? Could he/she be trained how to self-evacuate safely?)
- What modes of communication could he/she use to learn of emergency instructions or to contact one's support system or emergency personnel? Is there access to an appropriate telephone (hand free dialing, for example)?
- If the person has a service animal or pet, can he/she care for the animal in an emergency or make other plans?
- Assist the individual with identifying and enlisting a personal support network in case traditional supports, such as home health services, are not available.
- Ensure the individual has extra supplies on hand.
- Give friends and family copies of essential medical and disability-related information, including assistive devices and basic supplies, and instructions on how to use.
- Give extra house and car keys to friends and family who have been identified to help in case of an emergency.
- Practice emergency drills for evacuation in the event of fire, natural disasters, etc.

For the individual with multiple sclerosis, medications and wheeled mobility can present unique challenges. *Regarding medications:*

- If the person with MS uses self-administered medications, discuss purchasing a generator for home use, or a small portable refrigerator which can be charged with a converter connected to a car cigarette lighter.
- Have an insulated bag and supplies ready to use for a mobile kit.
- Suggest storing extra medication at the workplace or other location routinely used.

Regarding wheeled mobility, the person with MS should have:

- An extra battery (a car battery can be used but will not last as long).
- A patch-kit and can of seal-in air product in mobile emergency kit for tires.
- An extra supply of inner tubes.
- The ability to recharge or replace the battery in an emergency (jumper cables or converter for a car cigarette lighter).
- A lightweight portable wheelchair as a back-up.

For more detailed emergency procedure information, please go to Appendix E.

TIPS: Safety Issues

1. Access to telephones (large buttons, volume control, hand-free dialing, etc. when necessary) is important when there are emergency situations.
2. Access to light switches is important, particularly when the individual transfers at night or is in poorly lit areas.
3. Emergency access and entry must be clearly delineated and familiar to all concerned—individuals with MS, family caregivers, and home care workers.

Emotional and Family 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 care plan for people with MS.

FAMILY AND CAREGIVER ISSUES

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

Most people with MS who require home care services do not meet the traditional profile of those who generally use these services, particularly with regard to age. Much of 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 may be stretched beyond their emotional and physical resources by the demands of caregiving and need the services of a home care agency or other paid providers.

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. Home care can provide the family with the services required to avoid placing young children in inappropriate caregiving situations.

EMOTIONAL ISSUES

While each person's emotional reactions to a chronic, unpredictable disease like MS will differ, there are some fairly common emotions that the home care 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.

Guilt: 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.

DEPRESSION

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
- change in appetite
- disruption of normal sleep pattern
- physical discomfort
- difficulty thinking or concentrating
- thoughts of suicide or death

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

TIPS: Coping With Change

Home care staff can help individuals to cope with change by:

1. Encouraging expression of feelings.
2. Encouraging the individual to continue to pursue former interests.
3. Participating in training to understand the psychosocial, emotional and family issues related to MS and how they can affect daily routine and relationships.
4. Understanding depression in MS and how to be sensitive and appropriately responsive.
5. Recognizing the challenge for individuals who must make significant changes to their daily routines.

AFFECTIVE DISORDERS

Affective release (also known as “pseudobulbar affect” or “Involuntary Emotional Expressive Disorder” (IEED)) refers to unpredictable episodes of laughing or crying, often having nothing to do with the person’s underlying mood, or to an excessive response to some stimulus or provocation. 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.

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. For some, it might be a physical place. 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 individuals are important in helping them grapple with these issues.

EMOTIONAL ISSUES RELATED TO SEEKING HOME CARE SERVICES

Fear of the Unknown: Inviting a new person(s) into the home often raises anxiety—What will the home health aide (or personal care assistant) be like? Will the same person come each visit? What if he/she doesn't come? Does he/she know about MS? Will he/she come in and dictate changes and new methods of doing things without first spending time to understand how I do things now? I don't want someone here interfering with my scarce privacy, rearranging my furniture, clothes, cherished items. Can I trust these home care providers? I feel vulnerable because of my MS mobility problems.

Fear of Being Viewed as a "Failure": People bring their own personal meaning to illness and disability. Some may see illness as a punishment, others as bad luck and still others as a test of courage and spirit. When things are not going well and coping with MS is challenging, some people may see their lack of courage or spirit as failure. These feelings may feed depression and poor self-esteem, further reinforcing a sense of distress and self-disappointment.

Concern About Finances: Finances are often a major stressor in a home where an individual can no longer work. In particular, worries about covering the costs of home care may cause significant anxiety. Financial worries often create an increased sense of vulnerability—Will I be able to maintain the level of care I need? At what expense will home care be provided? Will my spouse have to work longer hours? Will we need to sell-off possessions or assets? *For information on the financial aspects of home care, please go to Appendix F.*

RISK OF ABUSE AND NEGLECT

In families where there is chronic illness and disability, the risk for abuse and or neglect may be higher. Stress, caregiver burnout, financial issues and limited support do not cause violence. However, these issues can further exacerbate an abusive situation and may likely lead to more severe abuse and neglect.

Home care staff are in a unique position to recognize signs of abuse and neglect, observe some interaction between family members and otherwise notice high risk factors in the home.

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

Caregiver has:

- a history of family violence.
- a history of threats toward caretakers or healthcare professionals.
- a history or current abuse of substances (alcohol, prescribed or illegal drugs).
- attitudes of dehumanization or devaluation toward patient with MS or a specific gender, rigid ideas about gender (sex) roles.

- signs of “burn-out”, including exaggeration of caregiving involvement or of caregiving assistance or the degree of MS disability.
- limited or impaired ability to provide care because of their own physical or mental health issues or other related factors.
- a criminal history, including assault or substance-possession convictions.
- unrealistic expectations of abilities or capabilities of the person with MS.
- a controlling attitude or forcefulness about patient rights or decisions, such as type, extent or location of care (initially may appear as overly concerned).
- inappropriate blame of person with MS or others for the disease.
- sudden changes in mood or hypersensitivity.

Person with MS has:

- little or no access to family, friends or community support—social isolation.
- chronic progressive disease that appears to exceed the caregiver’s ability to manage.
- family members who are financially dependent on them.
- symptoms of poorly managed mobility needs, bowel or bladder incontinence, problematic cognitive symptoms and/or personality changes or disease worsening.
- physical dependency that may make 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.
- past abuse or neglect by caregiver.

Physical indicators of abuse and neglect include:

- bruises or welts that cannot be explained by falls or bumps related to mobility problems; bruises in the shape of a hand, fingers or familiar object, bilateral bruising. Bruises are likely to be located in places that normally aren’t viewed or in places where they wouldn’t show—abdomen, thighs, buttocks, back, etc.
- burns that cannot be explained adequately or that are in the shape of cigarette butts.
- abrasions, e.g., marks on the neck or 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, such as skipped doses, over-medication, unaccounted for or missing 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 or unsafe living arrangements, e.g., inadequate heat, cooling, safety, electricity, access to telephone, architectural barriers.

Emotional or verbal indicators of abuse include the following:

- Individual appears uncommunicative, defensive or frightened in the presence of caregiver.
- There is reporting of verbal or emotional abuse.
- There is emotional upset or agitation.
- Appearance is withdrawn or apathetic.
- Unusual behavior is exhibited, such as rocking, sucking or biting.

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 home health agencies may have rehabilitation professionals on staff, others contract with therapists from the community and still others may refer clients when there is a distinct need.

Insurance coverage for rehabilitation services may be problematic for some people with MS since improvement and restoration may not be feasible goals. Maintenance of function and prevention of further disability are appropriate goals for many people with MS but are not necessarily recognized as reimbursable by third party payers.

REHABILITATION REFERRAL

Refer individuals to physiatrists, 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. A neurologist can often serve as a principal care provider, doing the initial assessment and sharing coordination of care with a primary care physician. Referral to rehabilitation professionals is important if there are 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. Rehabilitation professionals are also important in assessing the individual's need for seated mobility and other assistive technology.

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. A physical therapist can design a home exercise program targeting both MS and non-MS issues.

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 functioning.

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 and language pathologists: SLP) might include exercise, voice training, or the use of special devices.

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

Expressive Arts Therapy uses five art disciplines—visual arts, music, drama, dance, and poetry—to improve and enhance the physical, mental and emotional well-being of individuals of all ages. Its goal is to help reduce stress, increase self-esteem, and serve as a vehicle for self expression.

EXERCISE

Persons with MS should be cautious about engaging in vigorous exercise. It can increase core body temperature that may augment weakness or other symptoms.

- Exercise and fitness go along with general overall good health and wellness and should be carried out in conjunction with preventative care, with proper diet and avoidance of unhealthy habits such as smoking.
- Relaxation exercises should be part of the overall program with regard to wellness. Relaxation and exercise programs can reduce the effects of stress upon the body and improve the emotional wellbeing of an individual.

Swimming and alternative exercise programs such as yoga or Tai Chi with supervision are excellent choices for fitness. (Make sure pool temperatures are not too high, as heat can exacerbate symptoms.)

- An occupational or physical therapist may suggest a variety of exercises designed to compensate for lost function and/or improve overall strength, range of motion, and endurance. In a rehabilitation clinical setting, use of standing frames, adapted stationary bicycles (that can provide upper extremity exercise) and other pieces of exercise equipment can be used to provide a range of exercise and rehabilitation options.

ADAPTIVE EQUIPMENT

An occupational or physical therapist can evaluate an individual's functioning in the home environment and then make recommendations for special adaptive equipment to assist weakened muscles and ways to conserve energy to make the activities of daily living less fatiguing. Adaptive equipment for hygiene, housekeeping, cooking, laundry, etc. should be regarded as tools to augment faulty mobility, sensation and balance, a way of getting jobs done with more efficiency and conservation of energy.

Devices that might enhance ADL independence include:

- unbreakable dishware.
- strong hand rails on stairs or bathroom bedrails.
- big knobs on stoves, cabinets, ramps, even small ones from room to room if there is a slight change in elevation.
- seat in shower, flexible shower head.
- light switch near bed.
- rounded corners on furniture.

USE OF MOBILITY DEVICES

Use of mobility aids, such as canes, crutches and walkers may also offset the effects of weakness and preserve independence. A physical therapist, occupational therapist, physiatrist, or orthodist can determine the best mobility aids and assistive devices. If there is weakness of a foot and ankle, there will likely be foot drop and a compensatory technique is provided by an ankle orthosis. This can be used also to diminish the effects of spasticity by tilting the foot upward and it will keep the foot from turning inward or outward as well as reducing "foot drop". In addition to weakness, the brace will reduce imbalance and wear and tear on involved joints. It may enhance safety with reduction of falls.

A cane is usually carried in the hand opposite a weak limb. Walking is a reciprocal activity, the left hand going forward with the right foot and vice versa. A cane held on the side of weakness might cause an increase in limp. A cane is simply another mobility tool used to optimize the function of weak muscles and impaired balance. It might also allow a shift of weight off of a painful lower limb.

A forearm or Lofstrand crutch can provide greater stability than a cane when balance and/or more severe weakness are present. It requires less upper extremity strength than does a cane.

With pronounced weakness of both legs, two canes or crutches may be required. If balance is especially poor, a walker may be the proper assistive device. For those needing maximum stability, it may be better to use a walker without wheels. Some of the new improved walkers have larger wheels as well as seats. They move smoothly and allow one to turn “on a dime”. They allow one to sit and rest (with the brakes locked).

WHEELED MOBILITY

Because of severe physical disability (weakness, paralysis, tremors, spasticity, fatigue, sensory deficits, incoordination, visual deficits, etc.), people with MS frequently require power wheelchairs, some 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. Improper positioning can increase elasticity, generate pain, and result in loss of skin integrity.

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.

Scooters are extremely useful for people with MS. They are best used for people with some mobility or ability to walk and who have good trunk strength, can control their lower limbs, and can transfer on and off completely. They do not provide a good supportive seat for any length of time and therefore are not appropriate for one requiring good trunk support. Cognitive impairment, lack of judgment, or poor vision could be problematic in using a scooter or power wheelchair.

Reimbursement by third party payers for rehabilitation services may pose a challenge, but staff should be aware that people with MS may be eligible for automatic extensions of coverage for OT and PT. (*See Appendix G for more information about reimbursement.*)

TIPS: Wheeled Mobility

1. Understand the proper use of 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.
2. Remember to clear crumbs and food stains, clean up after episodes of incontinence, and clean up after outdoor use (clearing mud, leaves).
3. Understand proper positioning, e.g., the wearing schedule of splints, checking for skin breakdown or irritation, and proper use of other positioning.
4. Monitor the individual's ability to safely mobilize their wheelchairs or scooters and note when a referral for new equipment may be appropriate.

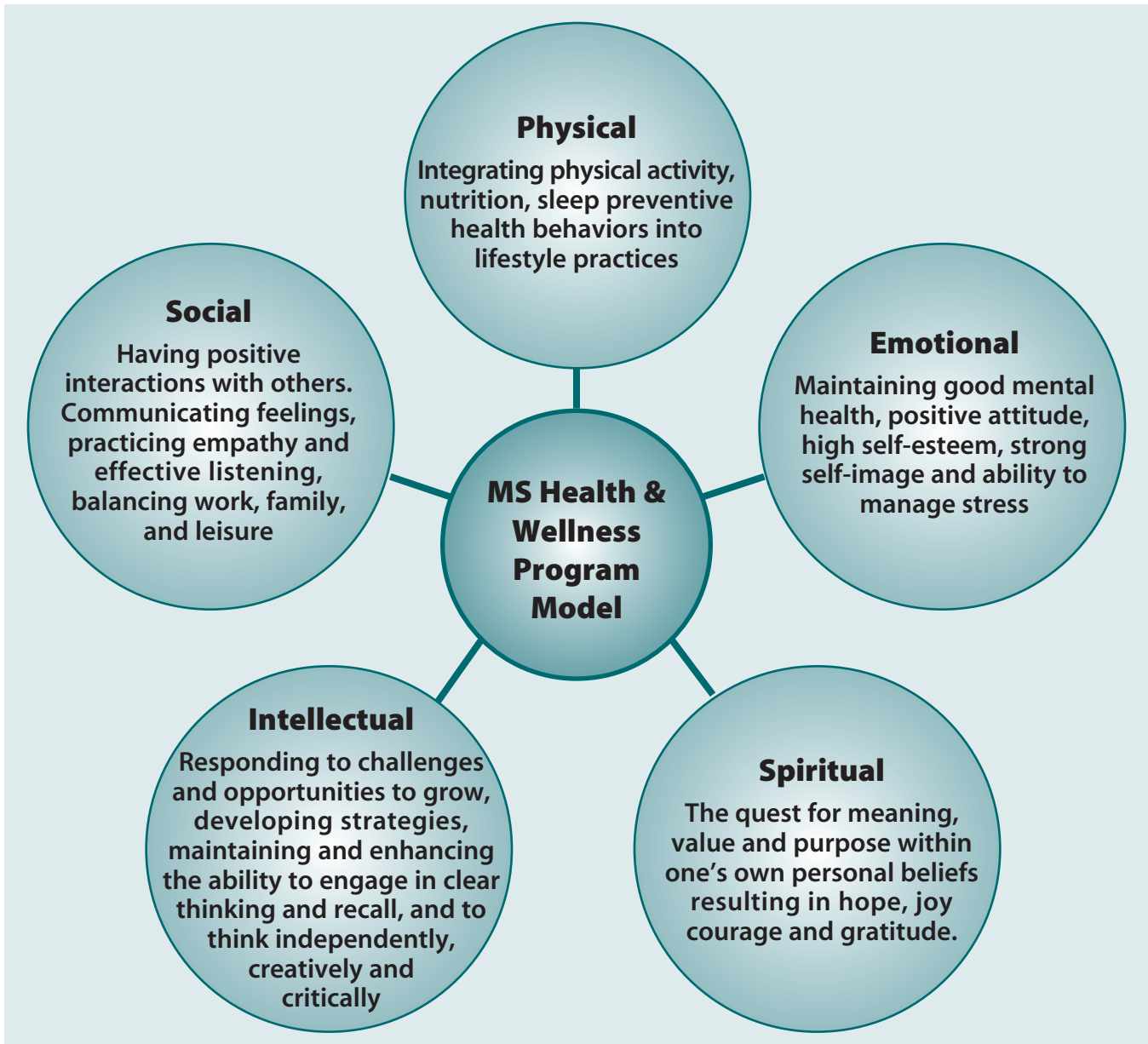
Wellness and Community Integration

Wellness can be described as a satisfying balance among the various aspects of health and well-being. Persons with MS have described wellness as feeling enabled, not disabled, motivated to do things, and connected to others.

The diagram below describes various health domains. Healthcare professionals should find ways to promote persons' productive and meaningful activity, especially when work and homemaker type activities are limited due to the MS. Caregivers should be aware of the many benefits of social and productive engagement, in order to support the person with MS in productive activities.

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

- **Physical Health:** Yoga, education and training in self-care, medication management, nutrition education, symptom management, personal health advocacy.
- **Social Health:** Community trips, dining out, shopping, cooking activities.
- **Emotional Health:** Peer counseling, individual psychotherapy, pet therapy, volunteer work, stress management, sharing personal knowledge and expertise.
- **Intellectual Health:** Current events discussions, reading, attending lectures, theater, movies, etc., computer activities, writing and journal keeping, continuing adult education.
- **Spiritual Health:** Meditation, relaxation, expressive therapies, religious activities, consultation with a religious leader or chaplain.



HEALTH PROMOTION AND WELLNESS

Health promotion and wellness should be encouraged by home care workers.

Computer Literacy offers many opportunities for intellectual stimulation, increased access to health information, social interaction through chat rooms and e-mail, and fun. Home health staff might direct the individual to resources to learn computer skills and access options for modifications of computer or software options for impaired vision and movement. (An occupational therapist can suggest these modifications.)

If a client does not have a computer, encourage him/her to explore places that provide access to the internet free. These can include the public library, public schools, senior centers, and various community organizations. A variety of agencies provide refurbished computers or assist with funding. Rehabilitation facilities may have departments that can adapt such equipment to compensate for a person's disability. Computers are increasingly used to pay bills, order groceries, record finances, etc., activities that can be made easier through information technology.

Driving: Some people with MS, despite significant mobility limitations, are able to drive, particularly with vehicle modifications. A driving evaluation can determine if the individual is safe behind the wheel and can determine what modifications may be necessary, e.g., hand controls. Help clients who cannot drive to explore accessible transportation options in their community and encourage participation in community events.

TIPS: Health Promotion and Wellness

1. Remind clients to keep routine health appointments with their primary care physician and dentist. Regular and preventive care (e.g., mammograms, etc.) should be encouraged. See section on Primary Healthcare Needs, pages 43–47.
2. Facilitate good nutrition and eating habits. Homemakers and other personal assistants who help the individual shop for and prepare food should keep in mind healthy eating, need for modified foods (e.g., thickeners) and provision of foods that are enjoyable to eat!
3. Facilitate fitness and exercise. Consult the physical therapist for advice on a home exercise program and if the use of modified exercise videotapes, stretching and strengthening routines, use of fitness equipment, etc. are appropriate.
4. Pay attention to sleep and relaxation. Help the individual access tapes for relaxation and stress the importance of conserving energy and rest times.
5. Help the individual manage his/her fatigue. Consultation with an occupational therapist about energy-saving strategies to perform ADLs may be of benefit.
6. Urge caution when the individual expresses interest in alternative approaches to health such as the use of alternative therapies or “natural” products. Stress the importance of discussion with their neurologist or their primary care physician on any use of “natural” or alternative approaches. Unsafe interventions, and/or those without a scientific basis which exhaust the reserves of an individual's and family's assets, should be avoided.

COMMUNITY RESOURCES

Help the individual find and use resources in the community. Maintaining life within the community is very important to people with MS. There are many services and programs available that can help to address disability issues and promote independence and community involvement. Before going to a new place, identify if the site is accessible.

- Each state has Centers for Independent Living (CILs) that offer a range of services including peer counseling, housing referral, assistance with obtaining personal assistance, medical equipment and more.
- Older persons can turn to Area Agencies on Aging and Senior Centers for resource information.
- Adult Day Programs may be a useful resource for some clients. Sometimes personal assistants accompany the client to the adult day program.
- Durable Medical Equipment suppliers sell or rent wheelchairs, lifts, hospital beds, etc.
- Vocational Rehabilitation Services work with people with disabilities who want to stay in or return to the workforce.
- The Veterans Administration and Paralyzed Veterans of America provide support services to veterans.

TRANSPORTATION

People with disabilities often rely on accessible transportation in order to continue to be engaged and involved in their communities. They need this transportation to get to medical appointments, do grocery shopping, get to employment or volunteer work, or participate in community events and activities. This means access to vans and buses that can accommodate a wide variety of wheeled mobility, from manual wheelchairs to technologically advanced power chairs.

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 can also be available, although the person with a disability is usually required to be out of the house and on the sidewalk for pickup.

If a person with MS is using accessible transportation, one must be sure that tie-downs and other safety features can accommodate his/her wheelchair and that drivers have received specialized training in serving a 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 people with MS, the time it takes to be transported must be considered when determining if a program or event is appropriate and practical to attend. Air-conditioning is also absolutely required for participants with MS.

Practical information about community-based accessible transportation services for people with disabilities can be found at: www.projectaction.org, a service of Easter Seals. This website has information on accessible travel options in cities across the U.S. and includes details on transit, paratransit, taxi, airport shuttles, and many other transportation services.