

SERVING INDIVIDUALS WITH MULTIPLE SCLEROSIS IN THE HOME

Guidelines and
Recommendations
for Home Care Providers
and Personal Assistants



National Multiple Sclerosis Society
Professional Resource Center

SERVING INDIVIDUALS WITH MULTIPLE SCLEROSIS IN THE HOME:

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Home Care Providers and Personal
Care Assistants

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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 home setting, but is not meant to substitute for, or to supersede, individualized physician treatment and advice.

INTRODUCTION

This document was developed by the National Multiple Sclerosis Society to be a practical resource to home care providers involved in the daily care of persons living with multiple sclerosis (MS). It can serve as a resource to home care agency administrators and nurses, home health care aides, personal care attendants, in-home respite workers, private duty nurses, and others who want to learn more about the disease to better understand and assist their clients, whether on an acute, short-term or chronic long-term basis. These guidelines, while addressing clinical and personal care issues specific to MS, could also apply to other chronic illnesses and/or disabilities as well.

The National MS Society is a leader in the initiation, support, and promotion of high quality, age-appropriate care options for people living with MS. Consistent with this responsibility, the Society brought together an expert panel of National MS Society staff and specialists in the fields of neurology, nursing, social service, rehabilitation, and home care to identify the key components of care for persons with MS receiving services at home. This task force, that also included people with MS and caregivers, contributed knowledge and clinical expertise to the preparation of this document.

HOME HEALTH CARE FOR INDIVIDUALS LIVING WITH MS

While some of the symptoms of MS are seen in other disorders and may be familiar to home care staff, MS presents unique challenges to the individual with MS and to his/her caregivers. It is important that care providers are aware of the ways these symptoms present in persons with MS, how they affect the individuals' day-to-day life, potential treatments, and strategies for management. These guidelines provide recommendations that are intended to promote the independence, personal decision making, wellness, and dignity of the individual with MS.

Although, the home care plan focuses on the person with MS, it must also involve family members and their network of friends and neighbors. Home care should facilitate self-direction—allowing the person with MS to be “captain of his/her ship”. To the extent possible, it should aim to enhance self-image and self-esteem, and maximize a sense of control over one's life.

Note: *This document will be used by a wide range of home health care staff. Some may have an extensive clinical background, others social service expertise, and still others direct personal care experience. Therefore, the way this document is used will vary from reader to reader.*

What Are Our Assumptions About Home Care Services?

Home care is intended to provide an individual who is living at home with individualized services that are developed collaboratively with him/her and the family to foster health and quality of life.

Services that may be provided in the home include:

- Health-related services (e.g., skilled nursing, medication management).
- Social services (e.g., family and personal support/counseling, facilitating access to social and recreational activities, care management).
- Personal care services (i.e., assistance with activities of daily living).
- Homemaker and chore services (e.g., assistance with laundry, meal preparation).

- Rehabilitation services (e.g., physical, occupational, speech therapies, durable medical equipment).
- Child care (special arrangements are generally required and availability and coverage vary from state to state).

What Do We Know About People with MS Seeking Home Care Services?

Research has been conducted comparing residents with MS and elderly residents living in nursing homes. Although similar studies have not been conducted in other long-term care settings, it is likely that the results of such research would be similar. Therefore, compared to the elderly home care client, individuals with MS are more likely to:

- Be younger.
- Be more mentally alert.
- Be more physically dependent.
- Experience greater incidence of depression.
- Have a larger network of family and friends involved in their daily lives.
- Have a greater need for socialization and mental stimulation.

In addition to these differences, younger people with disabilities experience a different set of losses due to where they are in their life cycle—work, building financial security, familial role, ability to actively parent, and loss of or diminished sexual functioning.

Client Profiles

Here are the stories of two people living with MS who use home health or personal assistance services (PAS). These profiles illustrate some of the situations and needs that may be characteristic of individuals with MS who use home health services.

Emma: Emma is a 59-year-old widow who lives alone in an apartment in a suburban neighborhood. She was diagnosed with MS at age 29 and while her disease slowly progressed over time, she raised two children and worked as an accountant until 3 years ago when her memory and ability to drive safely declined and her increased fatigue made it impossible for her to continue. Her adult children live out of town, but she has a sister and brother-in-law nearby who help out on the weekends and help with shopping and errands. She uses a manual wheelchair for mobility indoors and a scooter for long distances, and has extreme fatigue. Her immediate memory is poor and she experiences depression. Emma receives Social Security Disability Insurance (SSDI) and Medicare. She does not qualify for ongoing home health services through Medicare, so she pays for her home health aide with private, personal funds. She receives home health care every weekday for 2 hours in the morning and 2 hours in the evening. Her aide assists her with a shower, dressing and grooming in the morning, and preparation for bed in the early evening. Her aide puts out her medications each day. Emma is able to prepare simple meals on her own. Lately she has had a couple of hospitalizations for severe urinary tract infections. Following the hospitalizations Emma has experienced increased weakness and dependence in activities of daily living (ADLs). Medicare covered physical therapy through a home health agency immediately following the hospitalizations but discontinued the services as she improved. The services Emma receives are enabling her to stay at home and she hopes to continue to do so as long as she can manage.

James: James is a 34-year-old single male who was diagnosed with MS at 27. The course of his disease has been rapidly progressive. He uses a power wheelchair for mobility, wears a catheter, has severe spasticity that makes transfers a challenge. He is dependent for all activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs that are impacted include walking, bathing, dressing, grooming, transferring, toileting, etc. IADLs include meal preparation, laundry, check writing, grocery shopping, etc. James receives Medicaid and SSI for personal care assistance through his state's Medicaid personal care assistant (PCA) program. He receives 8 hours of personal care and IADL assistance each day including weekends from three assistants whom he has hired and trained himself. He has a large network of friends who visit and call regularly and he volunteers one afternoon per week at the local Independent Living Center. James' home is outfitted with environmental controls that operate his stereo, TV, phone and front door via voice commands. By helping him manage medical and personal care needs, his personal assistants help him to be as independent as possible.

What Are the Circumstances in Which an Individual With MS and His/Her Family Might Seek Home Care?

- The person with MS is experiencing a worsening in disability status with accompanying needs for assistance in ADLs and IADLs.
- The person with MS has experienced a recent hospitalization and is recuperating from an acute episode.
- There has been a recent loss of caregiver support through death, separation or divorce, teenagers going away to school or illness of a caregiver.
- The caregiver has diminished capacity to assist.
- Care needs are exceeding available abilities of family and friends.
- A decrease in the person's motivation and poor compliance with medical/nursing/rehab care.
- The person and/or the home situation are deteriorating visibly—poor personal hygiene, person appears disheveled, noticeable weight loss or gain, house unkempt or dirty, etc.
- The individual has been discharged from an acute care setting with significant medical needs.
- The caregiver/spouse/family are voicing “burn-out”. They may voice such concerns as:
 - “I’m overwhelmed”;
 - “No one cares”;
 - “I’m up all night, I can’t get any sleep”;
 - “I’m frustrated”;
 - “I have no time for myself”.

Challenges for Home Care Workers

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

Home care workers tend to be closer in age to clients with MS and may identify with them to a greater degree than with their geriatric clients. This may prove confusing for workers who may develop close friendships and “over-relate” to younger clients. A client may make sexual overtures to a worker or may be the target of sexual overtures by the care provider. These issues need to be anticipated with a younger client and addressed during training. Sensitivity training can be helpful to maintain appropriate relationships with younger clients.

THE HOME CARE TEAM

At the heart of any home care team is the person with MS. People with MS have lived with their disease for many years, understand their body, and can provide valuable information to professionals and home care workers involved in their care.

Due to the complexity of multiple sclerosis, the health care of an individual with MS often requires professionals from a variety of disciplines. No one professional can provide the expertise required to deal with the range of needs effectively. Several professionals consulting and working together provides for optimum care. By accessing the expertise of all appropriate professionals, problems can be identified quickly, symptoms and functional issues managed more successfully, and unnecessary complications avoided.

Ideally, a team of specialists knowledgeable about MS provides a coordinated effort working with the individual and the family to address the many challenges that MS imposes. In the real world, financial and other resource limitations prohibit the realization of an ideal interdisciplinary approach. To the extent possible, though, people with MS will benefit from a home care team that might include:

- Nurse
- Home health aide or personal care assistant
- Social worker
- Psychologist
- Physical therapist
- Occupational therapist
- Speech therapist
- Homemaker
- At times, there may need to be outreach to other services as well, such as attorneys, architects, financial planners, etc.

The composition of the care team in the home health setting may vary from agency to agency but in the home care setting, the physician usually acts as consultant and a nurse or social worker acts as the team leader. This individual is the liaison/point person with the discharge planner and other care providers and serves as care coordinator.

WHAT IS MULTIPLE SCLEROSIS?

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

What Causes MS?

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

What Are the Symptoms of MS?

The symptoms of MS may include tingling, numbness, painful sensations, slurred speech, and blurred or double vision. Some people experience muscle weakness, poor balance, poor coordination, muscle tightness (spasticity), or paralysis that may be temporary or permanent. Problems with bladder, bowel, or sexual function are common, and inordinate fatigue, probably the most common symptom, is often a major source of disability. MS causes cognitive changes such as memory loss, word-finding difficulty, and trouble concentrating in about 45–65% of people with the disease. Only in 10–15% of cases do more severe cognitive changes occur. For most people with MS intellect is preserved. MS also causes mood swings and depression (one study indicates that the risk of suicide in the MS population may be seven times that of the general population). Symptoms vary greatly in type and severity from one person to another and may come and go unpredictably.

Who Gets Multiple Sclerosis?

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

What Are the General Patterns of MS?

MS is an unpredictable disease. Symptoms vary greatly from person to person, and may vary over time in the same person. Periods of active MS symptoms lasting more than 24 hours are called exacerbations, attacks or relapses, and periods of recovery, complete or partial, are called remissions. The disease ranges from very mild and stable to intermittent to steadily progressive. At the time of diagnosis, most people have relapsing remitting MS with attacks that last days to weeks followed by periods of partial or total remission. The periods between relapses may last months to years. Some people experience a progressive disease course with steadily worsening symptoms. The disease may worsen steadily from the onset (“primary-progressive MS”) or may become progressive after a relapsing-remitting course (“secondary-progressive MS”).

Is It Easily Diagnosed?

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

Can MS Be Cured?

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

Can MS Be Treated?

Yes, to a degree. Seven medications are approved by the Food & Drug Administration (FDA) at the time of this publication—interferon beta 1-a (Avonex®), interferon beta 1-b (Betaseron®) and Extavia®, glatiramer acetate (Copaxone®), interferon beta 1-a (Rebif®), mitoxantrone (Novantrone®) and natalizumab (Tysabri®). These medications reduce the frequency and severity of attacks of MS and/or may delay or slow progression of the disease.

All are administered through either injection or IV. More medication options are on the horizon, including the first oral therapies to address the course of the disease. **Appendix A includes additional information on these MS medications.**

Many medications are available to reduce symptoms of MS, and many other drug therapies are being clinically tested. Either intravenous or oral steroid administration is a method of choice for management for acute exacerbations of MS.

There are also many non-pharmacological ways to address particular MS symptoms. Physical therapy, exercise, vocational and cognitive rehabilitation, attention to diet, adequate rest, and counseling can be effective in maintaining independence and quality of life. Many symptoms can be eased with medication and other therapy.

A wellness approach to this chronic disorder, with attention to diet, fitness, primary health care, mental health, and adequate rest will have a positive impact on the course of the disease. Stress reduction and energy conservation, elimination of unhealthy behaviors (smoking, excessive weight gain, etc.) and regular exercise will promote wellness. The goal is for individuals with MS to regain a sense of control and optimal health and to fulfill their potential.

What Are the Long-Term Needs Generated by MS?

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

The needs that are generated by progressive MS can be met by a continuum of age-appropriate and accessible long-term care services from care management and home care to adult day programs, assisted living and other community-based housing options. Nursing home care becomes necessary for about 5–7% of persons with MS.

CLINICAL ISSUES AND SYMPTOM MANAGEMENT

While some symptoms of MS are seen in other disorders and may be familiar to home care providers, the clustering and nature of these symptoms present a unique challenge to the individual with MS and his/her caregivers. The following symptoms of MS generate a wide variety of care needs. (Symptoms are presented in alphabetical order rather than in order of prevalence in persons with MS.)

Note: *Information about intervention and management is provided here to alert staff as to how these symptoms can be addressed and to describe the range of clinical experiences common to those with MS. It is not assumed that all of these interventions will be provided by home care staff.*

Balance Problems

What Is It? Balance problems cause an individual to feel unsteady and have difficulty maintaining his/her equilibrium and position in space. Balance problems in MS can cause difficulty walking characterized by unsteadiness with a drunken appearance (ataxia).

Psychosocial Impact. Balance problems may lead to falls. Some people with unsteadiness due to MS may appear intoxicated which can cause embarrassment or result in misinterpretation by others. Accepting an assistive mobility device may be difficult emotionally if it is interpreted as “giving in” to the disease.

Interventions: Equipment. A cane or other assistive mobility device can help to prevent falls when balance is poor. Since balance problems often co-exist with weakness and spasticity in the legs, assistive devices such as walkers, forearm crutches, and canes can offer support for weakness as well as for unsteadiness. If walking remains extremely difficult or impossible despite devices, a wheelchair may be the best choice to compensate for impaired balance and mobility.

Manual wheelchairs are often the preferred wheeled mobility in the home. However, for longer distances, when there is inadequate upper body strength, or when fatigue is severe, a scooter is a helpful alternative.

Interventions: Rehabilitation. Occupational and physical therapists can suggest strategies for improving or compensating for impaired balance and recommend the mobility aids that would be most helpful and appropriate. A therapist can usually come to the home and do an evaluation there.

TIPS: Balance Problems

1. The individual with MS may require close supervision, especially during transfers.
2. Handrails and grab bars strategically placed can provide safe and independent mobility, and canes or walkers help prevent falls for persons who are ambulatory.
3. Side trunk supports and seat belts (as positioning devices, not as restraints) are often recommended for seating balance. The appropriateness of these wheelchair features is best evaluated by specialists in seating and positioning such as occupational and physical therapists.

4. Supervised therapeutic exercises that challenge balance may be of benefit and supplement compensatory measures such as the use of assistive devices. These measures are best determined by rehabilitation professionals.

Bladder Dysfunction

What Is It? Bladder dysfunction is very common in MS and can occur in several forms. These include frequency and/or urgency of urination, incontinence, hesitancy in starting or maintaining urine flow or, in some cases, complete inability to urinate (retention). Frequent nighttime urination (nocturia) may interfere with sleep. Proper management is necessary to prevent urinary tract infections. Urinary retention may cause damage to the detrusor (the primary bladder muscle) and cause damage to kidneys due to back-up of urine into the kidney.

Psychosocial Impact. Losing control of one's bladder is a significant loss and a very upsetting symptom to an individual with MS. The need to urinate frequently or incontinence is discouraging and he/she may withdraw socially due to embarrassment or fear of having an accident. Regular, frequent visits to the bathroom are helpful but may be frustrating to family caregivers, personal care assistants or home care staff when there is need to assist on each occasion.

Interventions: Strategies. Many people with MS successfully manage bladder issues with self-catheterization. Intermittent catheterization 3–4 times per day is a common intervention, depending on the type of bladder dysfunction. This involves inserting a catheter directly into the bladder to empty the urine, and can be done easily and painlessly.

An indwelling catheter may become necessary if self-catheterization is not feasible. (See **Appendix B for detailed information about catheterization and catheter care.**) If leaking urine becomes excessive, a urologic assessment is advisable.

Some individuals report that cranberry extract in gel cap or tablet form is helpful for prevention of recurrent urinary tract infection. This may help by acidifying the urine to inhibit bacteria growth. However, the individual's physician should always be advised when such herbal preparations are being used.

Interventions: Medications. Medications such as oxybutynin (Ditropan XL[®]), tolterodine (Detrol[®]), and imipramine (Tofranil[®]) relax the detrusor muscle (the primary bladder muscle) and thus relieve symptoms of failure to store urine such as urgency and frequency, or incontinence. The major side effects of these medications are dry mouth and constipation, which may in turn need to be managed. Other medications that may help relieve retention, or the bladder's difficulty releasing urine: hyoscyamine (Levsinex[®], Levbid[®], Cystospaz[®]), and flavoxate (Urispas[®]).

Interventions: Surgical. Some individuals with MS may elect surgical procedures to manage incontinence. A suprapubic catheter is an indwelling catheter that is placed directly into the bladder through the abdomen. The catheter is inserted above the pubic bone. The insertion site (opening on the abdomen) and the tube must be cleansed by qualified medical personnel. The catheter may be attached to standard drainage bags.

TIPS: Bladder Dysfunction

1. To reduce urgency and/or bladder spasms the reduction of caffeine and carbonated beverages might be helpful. Dehydration should be avoided as dehydration produces concentrated urine that in turn can irritate the bladder and worsen symptoms.
2. If urgency is a problem, the bedroom should be close to the bathroom or a commode chair should be considered.
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 several 6–8 ounce glasses of fluid per day.
4. Individuals who leak urine should wear appropriate protection as indicated. The suggestion to wear pads or protective garments needs to be approached with sensitivity due to the individual's possible sense of humiliation and loss of dignity. Avoid brands that make noise when the individual walks. A protective pad should:
 - Cover the entire perineal area (urinary and bowel openings).
 - Have a hydro-colloid filling for greatest absorption.
 - Provide a thin profile and good absorbency.

5. The National Association for Continence is a well-established resource regarding incontinence issues. Contact information is located in the Resources section of this document.

6. Skin irritation or breakdown may ensue if the individual is frequently wet. The individual and caregiver should be taught how to inspect and protect the skin.

7. There are many types of leg bags that can be worn by individuals with indwelling catheters. These are not visible to others and thus will not interfere with social activities.

Bowel Dysfunction

What Is It? Bowel problems are frequent in MS. Constipation occurs in about one half of people with MS and is the most frequent bowel dysfunction, but fecal incontinence (involuntary bowel evacuation) is the most distressing and a source of social concern. Constipation is defined as having a bowel movement fewer than three times per week. Constipation in individuals with MS may derive from inadequate fluid and bulk intake, decreased or lack of physical activity, weakened abdominal muscles, anal sphincter muscle spasticity, and/or side effects of some MS-related medications. Diarrhea is defined as a condition of loose, watery stools occurring more than three times a day, and is not usually due to MS. Other medical causes need to be sought and treated.

Psychosocial Impact: Tendency toward bowel accidents often leads to social isolation and most people living with MS who experience accidents find this humiliating and embarrassing. Ambulatory safety problems can occur due to the nature of bowel accidents and emergencies.

Constipation: Constipation may be due to anal or pelvic floor muscle spasticity, decreased sensation or muscle weakness. Also MS involvement of the bowel, that causes slow transit of food stuffs through the bowel and increased water absorption, can lead to dry hard stool and difficulty with rectal evacuation or expulsion. Medications that cause constipation include analgesics, e.g., Codeine or Oxycontin®; anticholinergic agents to reduce bladder spasms, frequency, and urgency; anticonvulsants used for seizures, pain, and other sensory symptoms of MS; antidepressants such as imipramine (Tofranil®), amitriptyline (Elavil®), and nortriptyline (Pamelor®, Aventyl®); diuretics, iron, calcium, muscle relaxants, and anti-spasticity medications; antacids such as aluminum hydroxide (Gelucil®) and calcium carbonate (Tums®, Mylanta®, Maalox®); and anti-hypertensive agents such as verapamil (Calan®, Calan SR®, Covera-HS®, Isoptin®, Isoptin SR®, Verelan®, Verelan PM®).

Complications of chronic constipation include hemorrhoids caused by straining to have a bowel movement or anal fissures (tears in the skin around the anus) caused when hard stool stretches the sphincter muscle. As a result rectal bleeding may occur, appearing as bright red streaks on the surface of the stool. Sometimes straining causes a small amount of intestinal lining to push out from the anal opening. This condition is known as rectal prolapse.

Interventions: Strategies. Basic interventions to prevent and manage constipation for people with MS include increasing fluid and fiber intake, developing a routine bowel schedule, use of bulk formers, and use of stool softeners. Good bowel habits, such as establishing a daily, regular pattern of defecation with planned times for regular bowel evacuation, must be established and maintained. The best time for most people is 20 minutes after breakfast. Dietary management is important with adequate hydration and fiber. A high fiber diet includes raw fruit and vegetables, nuts, whole grain breads and cereals, cracked and whole-wheat barley, wild and brown rice, bran, etc. One should drink several cups (1 cup = 8 oz = 240–250 cc) of fluid daily. To establish normal stool consistency, bulk formers and stool softeners can be added. These agents allow water to penetrate the stool and soften it. Stool softeners and bulking agents are not habit forming nor do they irritate the bowel.

Interventions: Medications. Mild stimulants can be added when necessary (e.g., milk of magnesia). Glycerin suppositories provide lubrication, as do theravac mini-enemas that are not really enemas but lubricating stimulants in an easy-to-administer shell. More harsh stimulants and suppositories might at times be necessary (e.g., Dulcolax®).

Oral stimulants (e.g., Ex-Lax®) may be habit forming and should be used judiciously. Rectal suppositories provide chemical stimulants and lubrication to provide elimination of stool. These can be used on an as needed basis in conjunction with bulk-adding agents or oral stimulants. They act within 15 minutes to 1 hour. The use of suppositories sometimes allows for more bowel control in those with severe constipation. The use of enemas should be avoided however and used only when nothing else works. They can cause bowel dependence. They may be necessary for optimal scheduling of activities when suppositories do not work however. For this reason they may be the preference of some individuals on an as needed or regular basis.

TIPS: Constipation

1. Because of constipation and decreased rectal sensation, some persons may sit on a toilet for excessively long periods. Periodic reminders and checking is suggested.
2. Charting of bowel activity can be helpful.
3. Using the toilet or commode is highly preferable and usually more effective than using a bedpan. Mechanical factors improve defecation: the hips should be maximally flexed and if an individual requires a high toilet seat for transfer or mobility impairments, a foot stool may be helpful.
4. Gentle massage of the abdomen may help to compensate for weak abdominal muscles and facilitate bowel motility.
5. It is recommended that advantage be taken of the urge to have a bowel movement that occurs after meals (gastrocolic reflex), although this reflex may be impaired by MS. The gastrocolic reflex is strongest 20–30 minutes after consuming a warm beverage and/or warm meal. Many prefer to toilet after breakfast. One should sit comfortably on the toilet and if the bowels do not move after ten minutes, one should try again later when another urge might occur.

Diarrhea: Diarrhea may occur because of leakage around fecal impaction secondary to severe constipation or it can be a chronic condition for some people with MS due to an intestinal disease such as celiac, food intolerances or nerve damage. Diarrhea may also be due to overuse of laxatives. Incontinence is more likely to occur when diarrhea is present. Complications of diarrhea include skin breakdown at the rectum or in the buttocks area, urinary tract infection, weight loss, fatigue, and symptoms of dehydration such as low blood pressure and fainting.

Irritable Bowel Syndrome (IBS): Some people who have MS have a gastrointestinal syndrome known as irritable bowel (IBS) that causes cramping, bloating, gas, diarrhea, and or constipation. Most people with IBS have either diarrhea or constipation with the other symptoms. Diarrhea can become a dangerous problem when it lasts for a while (days or weeks) as dehydration can result, or it may be a signal of more serious problems such as a bacterial or viral illness, side effects from medications such as antibiotics, or a result of a parasite.

Cognitive Changes

What Is It? About one half of persons with MS experience changes in cognition, i.e., the skills involved in thinking, planning and organizing. In approximately 10–15% of these individuals, cognitive problems may be very severe to the extent that they may interfere with job performance and social skills. More often, changes are mild. Rarely will an individual with MS present with global dementia or disorientation. Specific cognitive deficits such as impaired short-term memory, decreased ability to multi-task and plan, impaired attention, diminished word finding, and impaired judgment and organizational skills, are found in MS. MS may affect cognitive impairments even when physical impairment is minimal. In general, intelligence in persons with MS who have cognitive change remains intact.

Psychosocial Impact. The reduced ability to process information in a timely manner and readily adapt to changing situations may cause a person to become dependent on caregivers and to isolate themselves because they can no longer “keep up”. Cognitive deficits may lead to an inability to continue work and these changes may cause self-image problems and embarrassment to the individual. Cognitive deficits may not always be readily apparent to family or co-workers and may be misinterpreted as laziness or depression.

Interventions: Strategies. The use of compensatory strategies can be helpful to minimize the impact of these deficits. Care providers should repeat information and write down important points. Follow up of verbal instructions with written back up, and use of visual aids, can be helpful. Encourage the client to keep a notebook, electronic organizer, or calendar to track important information.

Interventions: Rehabilitation. For an individual with MS, impairment of judgment, planning, and organizational function can have an impact on the safety of operating wheelchairs, especially power-operated wheelchairs or scooters. An occupational therapist should be consulted to address issues of safe driving (of both cars and wheelchairs) for individuals with MS who are experiencing cognitive problems.

Consultation with a neuropsychologist or speech and language pathologist may be beneficial to define areas of cognitive dysfunction that could be problematic in the future and hopefully prevent future trouble by providing compensatory measures.

TIPS: Cognitive Changes

1. It is important to have training in how to recognize and respond to people with cognitive deficits. Sensitivity and awareness of the cognitive and emotional issues that influence the behavior of the individual can help in managing behaviors more effectively.
2. The cognitive deficits associated with MS are to be differentiated from those associated with Alzheimer's disease and related dementias. In Alzheimer's disease, losses tend to be more global and the course is generally progressive, whereas in MS the course of cognitive change is variable. It can improve with management of an MS relapse and can be stable for long periods of time; or it may progress along with other MS impairments.
3. Recognize that an individual's ability to self-report may be impaired, but their awareness of his or her cognitive impairment will usually be greater than with older clients with dementia. Many individuals with MS who experience cognitive impairment are very aware of their difficulties and if they are depressed, may even overestimate the deficits. This increases their frustration and may decrease their willingness to try new things.
4. Develop consistent daily routines, yet try to provide stimulating and interesting strategies to help individuals use intact skills. Encourage puzzles and games that help with concentration, organization, and memory skills.
5. Activities requiring mental effort may be better accomplished early in the day, and for a short time period and/or with frequent rest periods.
6. Encourage the use of calendars, notebooks, and other prompts to address short-term memory issues.

Fatigue

What Is It? Fatigue is one of the most common symptoms of MS. MS fatigue is characterized by a total lassitude and lack of physical energy. People with MS may experience normal fatigue, fatigue of depression, fatigue of disease (cardiac and/or pulmonary, hypothyroidism, etc.), fatigue resulting from sleep disorder (such as sleep apnea and/or restless leg syndrome), or the fatigue of neuromuscular overuse. The fatigue of MS itself may be overwhelming and disabling, particularly with regard to motor and cognitive functions.

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

Psychosocial Impact. Fatigue is an invisible symptom. Others may misinterpret MS fatigue as laziness, depression, or poor motivation. Furthermore, since fatigue levels may fluctuate, family and friends may not fully understand its impact. Fatigue may be the key factor in an individual's ability to engage in social activities or perform daily tasks and work. Fatigue is one of the primary reasons for people with MS leaving employment. It also causes people to hesitate to plan for future activities for fear their fatigue will make it impossible for them to participate.

Interventions: Strategies. Napping is a good first step in managing MS lassitude. A short nap at an appropriate point in time will often be helpful in combating fatigue, although some people do not find rest to be restorative. Fatigue neither damages the nervous system nor causes demyelination, so it is not harmful for the individual to occasionally try to push themselves. Schedule rest periods after activity and before meals. Meditation and other relaxation techniques may be useful in managing fatigue.

Interventions: Medications. Appropriate medications for inordinate fatigue of MS include amantadine (formerly sold as Symmetrel®), fluoxetine (Prozac®), modafinil (Provigil®), and methylphenidate (Ritalin®).

Amantadine is an anti-influenzal agent that has empirically been found to reduce fatigue. The mechanism for doing so is unknown; Ritalin is a mild stimulant used to treat attention deficit disorders and childhood hyperactivity. Stimulants may be habit forming and may cause agitation, high blood pressure and palpitations. It is not known exactly how Provigil® works, but it appears to impact the sleep/wake cycle and augment vigilance. Provigil®, by expert consensus, has become the drug of choice for MS fatigue. Prozac® has dual effects on fatigue and depression. Sometimes, diaminopyridine or 4-aminopyridine, calcium channel blockers, can have an effect on motor fatigue.

Interventions: Rehabilitation. Consult with an occupational therapist who can recommend specific energy-saving techniques such as work simplification, pacing, planning, and balancing rest and activities. Maintaining mobility is important as de-conditioning adds to fatigue and muscle atrophy. Exercise is important to combat both.

TIPS: Fatigue

1. 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.
2. A sudden increase in fatigue may herald a relapse.
3. Overheating should be avoided to minimize fatigue in heat-sensitive individuals as would come with excessive exercise. Heating pads and electric blankets are best avoided.
4. Fatigue can have a deleterious impact on the ability to carry out activities of daily living during the course of the day. Home care workers must be aware that the individual may be independent in the morning, and require a great deal of assistance by the late afternoon.

Hearing Loss

What Is It? Hearing loss is not a frequent 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. 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.

Psychosocial Impact. Reduced ability to communicate effectively can have a serious impact on social interactions. The individual may be embarrassed, communicating may become a very tiring effort, and the individual may discontinue trying to engage socially. Home healthcare providers must be patient when communicating with an individual with hearing loss and not pretend they have understood when they have not.

Interventions: Rehabilitation. Speech/language therapy may be effective in assessing for hearing aids or other listening devices and in recommending other strategies to compensate for hearing loss. Audiologists can also assess the nature and extent of hearing problems and help individuals to manage them.

TIPS: Hearing Loss*

1. Face the person with hearing loss.
2. Get his or her attention before speaking.
3. Eliminate background noise as much as possible (e.g., turn off television, close doors, etc.).
4. Have the person with hearing loss have his or her back to the wall, so that sound reflects back to the ear.
5. Speak each word clearly and distinctly.
6. Avoid shouting, which distorts lip movements so they are harder to read and may sound angry.
7. Do not cover lips with hands, mustaches, or other objects.
8. Use complete sentences, so that the listener can use the context to identify meaning.
9. Use a different phrasing if the listener does not understand at first.
10. Spell words out or write them down.
11. Use facial expressions, gestures, and body language to help get the message across.
12. Make certain that light is shining directly on the speaker's face, and is not coming from behind the speaker.
13. Speak toward the better ear, if applicable.
14. Have the listener repeat back what he or she heard.
15. Make sure hearing aids are in place and working properly.
16. Make sure the listener is wearing his or her eyeglasses (if applicable).
17. Learn how to use assistive listening devices.
18. Ask the listener what is the best way to communicate with him or her.

*For more information and resources, please go to longevity.about.com and search "hearing tips".

Pain

What Is It? Some people with MS may experience tic-like pains or sharp stabbing pains without obvious cause. These may involve any body part, such as the face, in which case the pain is called trigeminal neuralgia or tic doloreaux. This is a sudden sharp, stabbing pain in the face that lasts seconds but may recur often in bursts and frequently throughout the day. It is very painful but often readily treatable by medication, frequently at low doses. On the infrequent occasion when facial pain is intractable and excruciating, it is usually amenable to a surgical procedure.

People with MS often over-use their stronger muscles in favor of weaker ones, and in doing so may injure those muscles and joints. Back pain is common and is often caused by abnormal movement, gait, or posture. The use of a walker or a wheelchair can result in overuse of the upper limbs that, in turn, can give rise to pain. Injuries to the shoulder and back are common. Incorrect transfer techniques of well-intentioned caregivers can result in injury and pain to the back and other areas.

Spasticity can produce painful spasms (see section on Spasticity, pages). Also, sensory disturbances can be painful. They may be perceived as a burning feeling, painful pins and needles or other unpleasant sensations.

Psychosocial Impact. Pain is very self-absorbing and may limit an individual's interest in social activities. Unremitting pain may also lead to depression. Pain itself can lead to decreased mobility, limiting an individual's ability to engage in activities that were previously enjoyed.

Interventions: Medications. The most effective medical treatment for pain should be directed to its source. A careful evaluation to determine the presence of injury, non-MS causes for pain, and exactly what type of pain is present is essential in order to choose the appropriate treatment.

Burning, aching, tingling pain of the legs sometimes responds to gabapentin (Neurontin®) or tricyclic drugs such as imipramine (Tofranil®). These drugs, particularly when required at higher doses, often cause side effects that in turn will need to be managed (constipation, weight gain, etc.).

Management of pain in MS is often a challenge but use of such agents as routine analgesics, propoxyphene (Darvon®), tramadol (Ultram®), anticonvulsants, antidepressant medication such as imipramine (Tofranil®), and nortriptyline (Pamelor®, Proventyl®) can be effective. Narcotics should be reserved for severe cases only and usually are not necessary. Sometimes referral to a pain clinic is indicated.

Interventions: Strategies. Heat or ice may be effective for relieving local pain in muscles and joints. However heat should not be used on the head, neck, and spine as it might exacerbate symptoms.

Some people with MS report that massage and relaxation techniques have helped them deal with their pain. This might be particularly helpful for pain of musculoskeletal origin such as sprain, strain and muscle spasm. These interventions should be considered only after consulting with appropriate health care professionals involved in the client's medical care. There is no reason to believe that these measures reduce other MS-related pain except perhaps by improving the pain threshold and making pain more tolerable.

TIPS: Pain

1. Some people with MS may experience burning or stinging sensations on their legs and feet that may lead them to prefer being barefoot or wearing slippers rather than shoes and socks, and may worsen with weight bearing, leading them to prefer a wheelchair over walking.
2. 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.
3. Staying active and maintaining a positive attitude often seems to be able to reduce the impact of pain.
4. Self-report is the single most important piece of pain assessment.
5. Rating pain on a scale of 1 to 10 can provide very helpful information.

Respiratory Muscle Weakness

What Is It? Weakness of the respiratory muscles due to MS may predispose the person with MS to pulmonary infection. While a simple cold may not pose a problem to most people, the presence of respiratory muscle weakness, inadequate deep breathing, and inability to cough increase the risk of developing pneumonia. Individuals with weak respiratory muscles might have impaired ventilation effort with difficulty clearing secretions.

Psychosocial Impact. It is advised that the individual limit exposure to others with upper respiratory infections and this may impact social activities, especially in the winter months. If the person with MS must be exposed, appropriate precautions should be taken, such as wearing a mask and keeping a distance of 6 feet from the other person.

Interventions: Strategies. Persons with MS should be encouraged to receive the influenza vaccine annually and the pneumovax every seven to ten years. Individuals with weakness of their respiratory muscles (intercostals, abdominals, and diaphragm) should be instructed in deep breathing exercises and encouraged to do these regularly. The individual should be turned every two hours if immobile. He/she should be encouraged to cough and to do deep breathing exercises. Postural drainage may be necessary to loosen secretions if an individual with severe MS is unable to cough effectively. Oral or nasal tracheal suctioning may be necessary.

Interventions: Equipment. A Mechanical Insufflation-Exsufflation (MI-E) device, used with a facemask or mouthpiece, clears retained bronchopulmonary secretions, reducing the risk of respiratory complications. The device (e.g., the “Cough Assist”) achieves this by gradually applying a positive pressure to the airway and then rapidly shifting to negative pressure. The rapid shift in pressure simulates a cough. Any patient unable to cough or clear secretions effectively due to weakness in respiratory muscles may benefit from this device. A respiratory therapist can provide an assessment to determine whether such a device would be appropriate.

TIPS: Respiratory Muscle Weakness

1. Preventive measures to limit spread of infection include:
 - Good hand washing techniques.
 - Use of a mask to prevent spread of infection, especially when working within 6 feet of a person.
 - Cleaning objects frequently to avoid spread of germs. These include doorknobs, telephones, remotes, keyboards, etc.
 - Keeping tissues handy; coughs and sneezes should be into tissues, not hands.
2. Breathing exercises during rest periods can promote relaxation.
3. Mechanical devices available to stimulate breathing such as the incentive spirometer may be of benefit. The individual and caregiver might be taught the techniques of respiratory therapy for home care purposes.
4. People with MS who have difficulty breathing often benefit from sitting upright (rather than laying flat).

Seizures

What Is It? Seizures, which are the result of abnormal electrical discharges in an injured or scarred area of the brain, are fairly uncommon among people with MS. Their incidence in persons with MS has been estimated at 2% to 5%. Paroxysmal symptoms in MS are brief sudden attacks of abnormal posturing of the extremities, loss of tone in the legs (“drop attacks”) or other manifestations that may appear similar to an epileptic seizure but are of different origin. Examples of paroxysmal symptoms include: intermittent pain (e.g., trigeminal neuralgia); spasms of an arm or leg; L’hermitte’s sign (electric shock-like sensation down the spine when the neck is flexed); Uhthoff’s symptoms (transient blurring of vision associated with exertion and elevated body temperature).

Psychosocial Impact. Those with seizures find them unpredictable, frightening and embarrassing. They may stay close to home or isolate themselves for fear of having a seizure in public. Those who observe an individual having a seizure often feel frightened and helpless. Symptoms such as paroxysmal vertigo may be disabling and frightening.

Interventions: Medications. Most seizure disorders can be well controlled by use of the appropriate anticonvulsant medication, such as carbamazepine (Tegretol®) or diphenylhydantoin (Dilantin®), and continuing medical supervision.

TIPS: Seizures

1. If a person has a seizure, stay calm, time the seizure, and protect the person from injury by placing something soft under their head and loosening tight clothing at the neck.
2. Provide reassurance and try to minimize embarrassment when the person is recovering from the seizure.
3. If a seizure occurs while a person is in a wheelchair, leave the person seated if secure and safely strapped in.

Sensory Disturbances

What Is It? 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.

Diminished sensation, accompanied by impaired mobility, can result in skin breakdown (pressure sores). Pressure sores are breaks in the skin caused by too much pressure over a period of time. When pressure is applied to an area for too long, blood flow becomes obstructed. The skin responds with redness and warmth. Other risk factors in the development of pressure sores include obesity (sores can develop in areas where skin touches skin causing friction, for example, between the legs and buttocks, or in an abdominal fold) and being underweight (where bony prominences particularly at the hips, buttocks, and back exist). Pressure sores occur more often when the skin is dry. Smoking causes tiny blood vessels to constrict allowing less oxygen and nutrients to reach the skin and its supporting tissues. A variety of medical conditions contribute to pressure sores such as diabetes and anemia. Mental confusion is a risk factor also. If one is not aware of the forces that are contributing to the formation of pressure sores, one cannot prevent them. See **Appendix C for the Braden Scale, used to assess risk for pressure sores.**

Psychosocial Impact. Diminished sensation may present a safety concern in bathing, in feeding, and for individuals who smoke (exposure to hot beverages and food, and to cigarette burns). With diminished sensation, people with MS might sustain injuries using their ambulation aids. Loss of sensation or discomfort to touch may affect a person's sexual activity.

Interventions: Strategies. Regarding skin breakdown, prevention is the best practice. Potential causes of pressure ulcers such as friction, shearing, moisture, and chemical damage should be avoided. Should pressure sores occur, they must be treated early. If allowed to progress, they can become life threatening. A pressure sore can evolve from a break in the skin to a large ulcer or hole that can expand into underlying tissue such as muscle and even bone.

With relief of pressure, recovery will occur. Factors that affect wound healing include adequate hydration (proper fluids) and nutrition. See the Tips below for recommendations on how to prevent pressure sores.

Interventions: Surgical. If all else fails, surgical closure of a wound may be necessary. The break in the skin, the ulcer cavity or opening with its surrounding scar, must be totally removed and the wound covered with healthy skin. Proper post-surgical treatment is critical. Care must be taken not to apply pressure or irritate the wound prior to healing. The area will remain vulnerable to re-injury.

TIPS: Sensory Disturbances

1. 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. Due to numbness, there may not be an “ouch” factor.
2. It is important to regularly look for signs of skin breakdown. Always tell the individual whom you are checking what you are going to do next.
3. To prevent pressure sores:
 - Individuals with MS should be kept moving and encouraged to continue activities that keep them mobile. Their position should be changed frequently and their weight shifted at frequent intervals. Wheelchair push-ups are helpful. If in bed for long periods, their position should be changed every two hours.
 - The individual with MS needs to practice good skin care, and to spot and alleviate problems as early as possible. He/she must inspect his/her skin at least once daily and might require some assistance in doing so. Special attention must be paid to common areas of pressure sores and to areas that remain discolored after changing position. The use of warm water and mild soaps when bathing is of benefit, and skin cream and oil should be used to prevent dry skin.

- Appropriate skin cream and ointment should be applied to protect the skin from urine and stool.
- A balanced healthy diet is important and if same cannot be maintained, a nutritional supplement would be of benefit to maintain appropriate nutrition.
- Impediments to healing should be identified and removed, such as malnutrition, lack of hydration, protein depletion, medications such as steroids and wound detergents, and areas of necrosis.
- Pressure should be diffused with a foam pillow or with an air or water mattress. Foam, rubber, or sheepskin pads are helpful to disperse the weight of the body over larger surface areas.

Sexual Dysfunction

What Is It? Sexual problems are often experienced by people with MS, but they are common in the general population as well. In MS, damage to nerve pathways involved in sexual arousal and orgasm can impact sexual functioning. Sexual problems also stem from MS symptoms such as fatigue or spasticity, as well as from psychological factors relating to self-esteem and mood changes. In a recent study, 63% of people with MS reported that their sexual activity had declined since their diagnosis.

In women, symptoms include reduced sensation in the vaginal/clitoral area, or painfully heightened sensation, vaginal dryness, trouble achieving orgasm and loss of libido. In men, symptoms include difficulty achieving or maintaining an erection (by far the most common problem), reduced sensation in the penis, difficulty achieving orgasm and/or ejaculation and loss of libido. Other MS symptoms cause problems in both sexes: fatigue and weakness can interfere with sexual interest and/or activity; spasticity can cause cramping or uncontrollable spasms in the legs, causing them to pull together or making them difficult to separate—either of which can make positioning difficult or uncomfortable; pain can interfere with pleasure; embarrassment can be caused by bowel or bladder incontinence.

Psychosocial Impact. The emotional factors relating to changes in sexual function are quite complex. They may involve loss of self-esteem, depression, anxiety, anger, and/or heightened stress.

Interventions: Strategies. Counseling by a mental health professional or trained sexual therapist can address both physiologic and psychological issues. This therapy should involve both partners. Both men and women with MS and their partners can benefit from instruction in alternative means of sexual stimulation such as the use of a vibrator to overcome slow arousal and impaired sensation. Abnormal sensations and spasms can often be controlled through the use of medication. Strategies such as intermittent catheterization or medication can control urinary leakage during intercourse.

Interventions: Medications. There are a variety of therapies to treat sexual dysfunction. For men, erectile dysfunction may be addressed through: use of the oral medications sildenafil (Viagra®), vardenafil (Levitra®), and tadalafil (Cialis®); injectable medications such as papaverine and phentolamine that increase blood flow in the penis; the MUSE system which involves inserting a small suppository into the penis; inflatable devices; and implants.

For women, vaginal dryness can be relieved by using liquid or jellied, water-soluble personal lubricants that can be purchased over-the-counter. It is a common mistake to use too little of these products. Specialists advise using them generously. Petroleum jelly (Vaseline) should not be used because it is not water-soluble and may cause infection.

TIPS: Sexual Dysfunction

1. Encourage clients who mention sexual problems to talk with their physicians or another trusted health care professional.
2. Reassure them that many people with MS experience sexual problems.
3. Suggest they go to the National MS Society website (nationalMSSociety.org) for more information.

Spasticity

What Is It? Spasticity refers to feelings of stiffness and a wide range of involuntary muscle spasms (sustained muscle contractions or sudden movements). It is one of the more common symptoms of MS. Spasticity may be as mild as the feeling of tightness of muscles or may be so severe as to produce painful, uncontrollable spasms of extremities, usually of the legs. Spasticity may also produce feelings of pain or tightness in and around joints, and can cause low back pain. Although spasticity can occur in any limb, it is much more common in the legs.

A contracture is a freezing of a joint that reduces its range of motion. It occurs when the joint has not been kept mobile and usually results from spasticity, disuse, and lack of exercise, especially range of motion and stretching exercises.

Psychosocial Impact. Spasticity and tremors are involuntary, reinforcing a sense of being out of control of one's body and movement. Spasticity can interfere with mobility and sexual activity and be a source of embarrassment. Spasticity can also interfere with transfers and personal care.

Interventions: Medications. The most common medicines used to reduce spasticity are baclofen (Lioresal®), and tizanidine (Zanaflex®). Other, less commonly used medications include: diazepam (Valium®), dantrolene sodium (Dantrium®), phenol, a nerve block agent, and botulinum toxin (Botox®) injections.

Interventions: Rehabilitation. Rehabilitation management of spasticity may include a stretching program and training in correct positioning. A physical or occupational therapist can train individuals and caregivers in the best positioning techniques to control spasticity.

Contractures and the resulting decrease in range of motion can lead to mobility problems, skin breakdown, sepsis and even death. Maintenance of range of motion is key to preserving functional mobility. Daily stretching should be performed and can be taught to family members as well. Each joint should be slowly moved to its full range of motion. In addition, proper positioning techniques in bed and chair are important. Another preventative measure includes walking and standing if the individual is able to do so. Standing in a standing frame may be helpful if the individual has the bone density to support his/her weight. In the lower extremities, the muscle groups most likely to be impacted by contracture and by spasticity are the hip and knee flexors, and the plantar flexor (pointer) of the foot. These muscles have a significant impact on everyday function, seating, and bed positioning. A home exercise program that focuses on these muscle groups twice daily can be helpful.

Once a contracture has occurred, the joint must then be slowly mobilized; icing before stretching may ease discomfort. Orthotics, such as splints or braces to maintain good positioning for the wrist, hand, fingers, foot, and toes are often effective in maintaining range of motion and preventing limitations that lead to deformity. Serial casting designed to stretch the joint may be of benefit. Once a contracture has occurred, it must be treated aggressively.

Interventions: Surgical. In patients with severe spasticity a programmable pump implanted in the abdomen that delivers a liquid form of baclofen directly into the intrathecal space where fluid flows around the spinal cord is a viable option. Because the drug is delivered directly to where it is needed in the spinal canal, it does not circulate throughout the body in the blood. This helps minimize side effects that may accompany oral baclofen. (See **Appendix D for more detailed information on the baclofen pump.**)

A joint that is frozen may become very painful and interfere with function. Occasionally, a surgical procedure to restore range of motion at the joint may be necessary. In every individual, it is easier to prevent than to correct contractures.

TIPS: Spasticity

1. 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 the jerking part or by change of position of the involved limb.
3. Quick jerking, sudden movements that can set off spasm should be avoided; guide the person with spasticity to move slowly and smoothly.
4. Stretching exercises should be carried out in addition to passive range of motion. Stretching is meant to be slower and positions are held longer. Training in stretching exercises and range of motion can be provided by a physical therapist or physiatrist. A typical maintenance schedule is 20 minutes three times a week.
5. People with spasticity who are ambulatory often are better off and safer if they use a cane or walker which helps to stabilize balance in walking and transferring.
6. An unusual increase in spasticity may be indicative of a bladder infection with or without fever, change in metabolic status, urinary retention, or fecal impaction.

7. Some individuals report positive outcomes from massage therapy and other relaxation techniques. The decision whether a client should pursue these interventions should be made in consultation with their physician. If considering massage therapy it is important to ascertain that the therapist is certified and that references are obtained.
8. If using assistive technology with a client who has spasticity be sure that adequate training in the use of the equipment is provided. This training must be individualized, as each person's abilities differ.

Speech Problems

What Is It? Speech abnormalities are relatively common in MS; dysarthria is the most common problem. Dysarthria is characterized by slurring of speech or alteration of normal speech rhythm. It may be manifested by severe difficulty with pronunciation and articulation, making communication difficult. Some people with MS slow down speech and have word-finding difficulty, making ordinary conversation problematic. Hypophonia, a problem with volume control, may also be present. When severe, amplification with a microphone may enhance communication. Speech problems often become more pronounced during times of stress or fatigue.

Psychosocial Impact. Reduced ability to communicate effectively can have a serious impact on social interactions. The individual may be embarrassed, communicating may become a very tiring effort, and the individual may discontinue trying to engage socially.

Interventions: Rehabilitation. Speech/language therapy may be effective in improving dysarthria, hypophonia and language. Also, speech and language pathologists may be able to recommend assistive devices to aid communication, such as voice synthesizers, voice amplifiers, and computerized communication devices.

TIP: Speech Problems

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

Swallowing Difficulties (Dysphagia)

What Is It? While swallowing is not a problem for most people with MS, some may experience difficulty swallowing or be prone to choking.

Psychosocial Impact. Eating is often a social activity involving family and friends. Swallowing problems can interfere with this previously enjoyable and relaxing social event. Furthermore, eating is a pleasure for most people. Inability to eat certain foods and requiring pureed or thickened foods may reduce the pleasure one previously took in eating.

Interventions: Strategies. Changing the consistency of food by increasing bulk, or making it easier to swallow by using a commercially available thickening agent or gelatin, may help to prevent possible choking and aid in assuring adequate nutrition. Rest periods before meals can also be helpful. For more severe problems and frequent difficulty a respiratory therapist can install suction apparatus and instruct caregivers with regard to its use.

Interventions: Rehabilitation. Coughing during meals may signal aspiration and should suggest the need for swallow evaluation and therapy. Interventions to address swallowing problems are generally performed by a speech and language pathologist and/or occupational therapist. These include: (1) an assessment that includes usually a modified Barium swallow test performed under fluoroscopy in the x-ray department; and (2) swallow “therapy”.

Interventions: Surgical. In extreme cases, it may be important to have a feeding tube placed directly into the stomach or small intestine; this is done under local anesthesia. Called a PEG—percutaneous endoscopic gastrostomy—this may help maintain nutrition and hydration. As people with feeding tubes become better nourished and hydrated, they may have a better ability to take some food by mouth. This must be determined by a speech therapist or other professional who can assess swallowing.

TIPS: Swallowing Difficulties

1. Thickened tea and coffee are much more palatable when served iced than when warm. Such iced drinks should resemble a milkshake in texture and taste.
2. When 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 individual eats slowly, and a microwave is handy, reheat food after 20 minutes to make it more palatable.
5. Learn how to perform the Heimlich maneuver.
6. Encourage the person to refrain from talking while eating. Choking often occurs when these two activities are simultaneous. Attention should be focused solely on the swallow mechanism.
7. The swallow mechanism may fatigue as the day goes on; if this is the case, the majority of caloric and nutritional intake should be switched to the early part of the day (breakfast and lunch).
8. Alternating fluids and solid foods helps to prevent sticking.

Tremor

What Is It? 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 or action tremor and may greatly impair functions such as reaching or grasping or the 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.

Psychosocial Impact. Individuals with tremors may find them exhausting, embarrassing and disabling. They may significantly interfere with social activities. Contrary to many symptoms of MS that are invisible to others, tremor is a very obvious symptom and can seriously interfere with eating, writing, even giving a handshake to someone.

Vision Deficits

What Is It? MS may affect vision in several ways. Abnormalities in activation of muscles that move the eyes may result in difficulty focusing on objects with resultant blurring or even double vision. Rarely an individual might see the world as constantly in motion or jumping (oscillopsia). Malfunction in the brain centers that control eye movement may also result in jerking movements of the eyes, known as nystagmus. In addition to problems focusing, this can also cause vertigo and dizziness 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 small minority of cases, severe visual loss which persists. Optic neuritis usually clears completely or nearly completely, only rarely leaving 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.

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

Interventions: Rehabilitation. Some individuals may benefit from a consultation with a neuro-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, is not correctable with lenses. Occupational therapy can help in devising adaptations for persons with visual problems.

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 individuals 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 font size of 14.

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. Keeping items in the same place and not moving things around can also be helpful.

Weakness

What Is It? Muscle weakness is a common symptom of multiple sclerosis. Weakness causes problems such as foot drop and dragging of one leg or the other or both. It can also cause buckling of the lower limbs, difficulty going up and down stairs, and difficulty with walking. Weakness of the upper limbs can be problematic in carrying out activities of daily living; often there is a loss of dexterity of fine movement, clumsiness, slowness of movement, and loss of power. Ability to assist in transfers can be seriously impacted.

Weakness results from disuse or from interrupted neurotransmission. Strengthening exercises may improve the power of muscles that are weak from disuse, but not from weakness secondary to poor or lost neurotransmission. The management of weakness must be done together with that of spasticity and fatigue to be effective.

Psychosocial Impact. Reduced mobility secondary to weakness may significantly impair an individual's ability to get out into the community and participate in social and community activities. Weakness probably means the person with MS requires more hands-on assistance from family members.

Interventions: Rehabilitation. If and when walking fails, the correct equipment is a must and one must learn how to use and maintain it. Mobility devices offset the effects of weakness. If necessary weak muscles must be substituted by mobility aids such as orthoses, canes, crutches, scooters, or wheelchairs—manual or power, in order that an individual with MS might preserve his/her independence and safety.

Physical therapy can help strengthen weakened, unconditioned muscles and improve balance and endurance. PT might include range of motion exercises, stretching, strengthening, assistance with walking (gait training), and the selection of assistance devices such as canes, walkers, wheelchairs, etc. Physical therapists should train an individual in the use of a new mobility device. Physical therapists can also supervise exercises that increase overall function such as aerobic or cardiovascular training.

A physical therapist should review health club, personal trainer, or gym activities to make sure these activities are appropriate, given an individual's special needs and impairments. Tai Chi, yoga, aquatherapy, and other complementary therapies may be helpful in maintaining range of motion and promoting relaxation. Individuals should always keep their physicians advised of such activity. Such programs are often run in conjunction with the National MS Society. It is preferred that they are supervised or run by individuals with a knowledge of MS.

Occupational therapy offers compensatory techniques for physical and cognitive problems, energy conservation, work simplification, and strengthening upper limbs to build tolerance for activities of daily living. 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.

Choosing features and fitting 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 and sometimes with a vendor of such equipment and/or a physiatrist.

TIPS: Weakness

1. Power wheelchair batteries need to be recharged each day. They should not be recharged with an individual sitting upon them. They should be recharged when the individual with MS is not alone at home. When charging the battery, the scooter or power chair must be turned off and the key removed. It is a good idea to have a smoke alarm located over or near the charging area.
2. It is important to be trained in appropriate transfer methods. Improper transfer can lead to injury both in the individual and the caregiver. See page 61 for information on body mechanics in transfer.
3. Wheelchairs and rollator walkers should always be in a locked position before transfer is attempted.
4. Wheelchairs should 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.
5. A belt around the waist can improve safety and function by providing those who assist with something to hold on to during a transfer.

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?

Domains of Health That Should Be Assessed Periodically (cont.)

Domain	What to Assess
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?
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?

Domains of Health That Should Be Assessed Periodically (cont.)

Domain	What to Assess
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 HEALTH CARE 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 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:

- PAP smear/gynecological exam annually (based on history and risk)
- Clinical breast or testicular examination annually after age 20–25
- Annual mammography 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 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. Those already being treated for high cholesterol should be checked every two to six months.
- Vision and glaucoma 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 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 to hormone replacement therapy that should be addressed by the person with MS and his/her physician. Thrombo-embolic risk, particularly that of deep vein thrombosis, is especially relevant in the person with MS who has mobility problems and may tend to be sedentary, particularly if 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, or coronary artery disease.

Deep Vein Thrombosis (DVT): With regard to the risk of deep vein thrombosis and its particularly dangerous complication pulmonary embolus, persons with MS who are immobile and/or tend to be sedentary, particularly if overweight, should consider with their physician whether or not to be anti-coagulated and if so, which anticoagulant is appropriate. It is important for people with MS to discuss the risks and benefits of such therapy with their 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 osteoporosis medication, are 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 overzealous 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 temporary intubations 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 living with MS depend on assistance for their activities of daily living. The type and degree of help needed will vary from person to person 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, we highlight issues in the following section that may be unique to assisting home health clients with MS.



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

Bathing/Showering: A younger client may prefer showers more frequently than a geriatric client. Transfers to the tub or shower can 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 in a wheelchair if accessibility of the bathroom presents a problem.

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, 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 Swallowing Difficulties, pages 40-41).

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/or 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) that operate TVs, phones, stereos, door locks, etc. with voice control or manual switches, adapted computers, communication devices and other technologies 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 de-conditioning. Overall, exercise is good. However the wrong exercises can generate injury and pain. A home exercise program should 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 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. Homemaking staff can be helpful 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 usually important to younger clients, and scheduling ADL tasks to avoid periods of fatigue is 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 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 19-23).

Transfers: Home health clients with MS are often heavier (they are younger and less frail than the elderly) and because of MS spasticity, spasms, and paralysis are usually more dependent in transfers than geriatric clients. Many may require the 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 lumbar 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.

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 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.



Cane



Quad Cane



Walker



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 can represent a safety concern, particularly regarding feeding (hot food and beverages), bathing (hot water), and smoking (burns). Individuals 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. Impaired judgment can impact safely operating a power-operated wheelchair or scooter. There can 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 the client smokes, 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.

Interventions: Rehabilitation. 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 can make recommendations for re-arrangement of furniture, removing small area rugs, installation of grab bars or use of other adaptive equipment to minimize 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.

Interventions: Environment. Adjustable heat and air conditioning are necessary to avoid accidents related to increased weakness and other symptoms generated by an increase in core body temperature or 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.
- Have the client give friends and family copies of essential medical and disability-related information, including assistive devices and basic supplies, and instructions on how to use.
- Have the client 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 home of a neighbor or relative.

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—the individual with MS, family caregivers, and home care workers.

EMOTIONAL AND FAMILY ISSUES

MS can make severe emotional demands on those living with the disease. Individuals and families are often 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.) can be significant areas of concern for this younger population. Access to social work or psychiatric support is an important feature of any care plan for people living with MS.

FAMILY AND CAREGIVER ISSUES

Home care services can bring great relief to family caregivers. These services can 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 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 likely provided by family members. These family caregivers are also not typical.

Caregivers of people with MS are often **working spouses** who may also have child care responsibilities. Due to the demands of caregiving, caregivers may be stretched beyond their emotional and physical resources and need the services of a home care agency or other paid providers.

Some caregivers are **elderly parents of adults with MS**. Issues that these caregivers face include the 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 of the disease increase and abate.

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 very 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 can 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

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.

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.

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 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 identifying, obtaining and managing these resources. In other words, he or she must 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, and 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 can 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 lead to more severe abuse and neglect.

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

The following are associated with high risk of abuse, but are not precise predictors:

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 can 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 can be problematic for 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 slowing of progression is unfortunately not always recognized as worthy of reimbursement by third party payers.

REHABILITATION REFERRAL

Referral to psychiatrists, occupational therapists (OTs), physical therapists (PTs), speech and language pathologists (SLPs), neuropsychologists, psychiatrists, and other appropriate professionals (e.g., orthopedists, orthotists, assistive technology experts) is important when addressing 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. Referral to rehabilitation professionals is important if there are changes in mobility, slurred speech or an increase in difficulty communicating and/or swallowing, an increase in stiffness or spasticity, increased tremors, fatigue that is interfering with functioning, etc. Rehabilitation professionals are critical for 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) can 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

Although persons with MS should be cautious about engaging in excessive and vigorous exercise, as it can increase core body temperature and weakness or other symptoms, reasonable exercise can be very beneficial.

- 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 can suggest a variety of exercises designed to compensate for lost function and/or improve overall strength, range of motion, and endurance. In 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 can 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

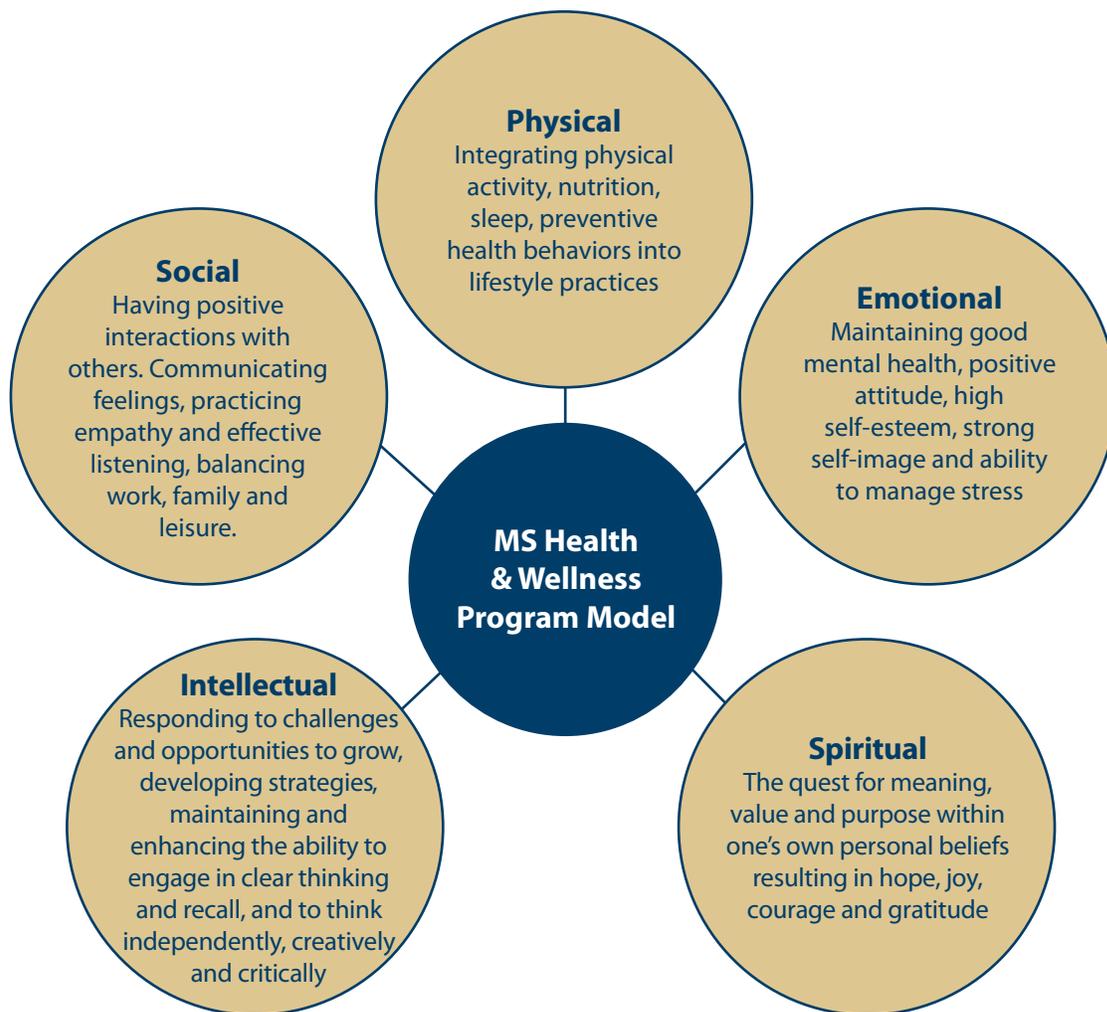
Wellness can be described as a satisfying balance among the various aspects of health and well-being. Persons living with MS have described wellness as feeling enabled, not disabled, motivated to do things, and connected to others.

HEALTH PROMOTION AND WELLNESS

The diagram on the next page 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.



Computers: Computers offer 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 and/or enhance computer skills and access 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 provides refurbished computers or assists 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 49–54.
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 your client 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.

DISEASE-MODIFYING MEDICATIONS FOR MS

There are now seven disease-modifying medications approved for use in relapsing forms of MS by the US Food and Drug Administration (FDA). None of them is a cure for MS. However, all of them have been shown to reduce disease activity and slow disease progression.

TREATMENT OPTIONS

Avonex[®], Betaseron[®], Copaxone[®], Extavia[®], and Rebif[®] are self-injectable drugs for long-term use; they modulate the immune system. Avonex and Rebif are two different formulations of interferon beta-1a; Betaseron and Extavia are the identical formulation of interferon beta-1b distributed by different companies. Novantrone is an immune system suppressor, delivered by IV infusion in a medical setting; Tysabri is an immunomodulator that is administered monthly by IV infusion.

Disease-Modifying Medications for MS		
Brand Name	Generic Name	Manufacturer/ Distributor and Year of FDA Approval
Immunomodulating Drugs		
Avonex®	interferon beta-1a	Biogen Idec, 1996
Betaseron® Extavia®	interferon beta-1b	Bayer HealthCare Pharmaceuticals, Inc., 1993 Novartis Pharmaceuticals, Inc. 2009
Copaxone®	glatiramer acetate	Teva Neuroscience, Inc., 1996
Rebif®	interferon beta-1a	EMD Serono, Inc./Pfizer, Inc., 2002
Tysabri®	natalizumab	Biogen Idec/Elan Pharmaceuticals, Inc., 2006
Immunosuppressant Drug		
Novantrone®	mitoxantrone; as of 2006, available as a generic drug	EMD Serono, Inc./ ImmuneX Corporation, 2000

Disease-Modifying Medications for MS: Indications

Immunomodulating Drugs

Brand Name	Indications (taken from FDA-approved labeling)
Avonex®	For treatment of relapsing forms of MS, and for a single clinical episode if MRI features consistent with MS are also present
Betaseron®	For treatment of relapsing forms of MS and secondary-progressive MS with relapses
Copaxone®	For treatment of relapsing-remitting MS
Extavia®	For treatment of relapsing forms of MS and secondary-progressive MS with relapses
Rebif®	For treatment of relapsing forms of MS
Tysabri®	For treatment of relapsing forms of MS as a monotherapy (i.e., not used in combination with any other immunomodulating therapy); generally recommended for patients who have had inadequate response to, or are unable to tolerate, alternative MS therapies such as those listed above

Immunosuppressant Drug

Novantrone®	For treatment of worsening relapsing-remitting MS and for progressive-relapsing or secondary-progressive MS
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Disease-Modifying Medications for MS: Dosage and Route of Delivery	
Immunomodulating Drugs	
Brand Name	Frequency, Route of Delivery, and Usual Dose
Avonex®	Once a week; intramuscular injection; 30 mcg
Betaseron®	Every other day; subcutaneous injection; 250 mcg
Copaxone®	Every day; subcutaneous injection; 20 mg (20,000 mcg)
Extavia®	Every other day; subcutaneous injection; 250 mcg
Rebif®	Three times a week; subcutaneous injection; 44 mcg
Tysabri®	Every four weeks by IV infusion in a registered infusion facility; 300 mg
Immunosuppressant Drug	
Novantrone®	Four times a year by IV infusion in a medical facility; lifetime limit of 8–12 doses over 2-3 years (140 mg/m ²)

DRUG SIDE EFFECTS AND WARNINGS

Managing Side Effects of the Self-Injectable Drugs

The flu-like side effects of the interferon products—Avonex®, Betaseron®, Extavia®, and Rebif®—can usually be minimized. Strategies can be discussed with the physician, or with the patient support program of the drug company, which is available through a toll-free number (see Industry-Sponsored Sites table below). Should unacceptable side effects occur, clients can explore the possible change to another drug with their healthcare professional.

The drugs that are injected subcutaneously, including Copaxone®, Rebif®, Extavia® and Betaseron® may cause injection site reactions, including bumps, bruises, pain, and infections. Good injection techniques can minimize problems. Auto-injecting devices may be helpful. The drug company patient support programs offer injection training and helpful tips for avoiding or limiting site reactions.

Disease-Modifying Medications for MS: Common Side Effects*

Immunomodulating Drugs	
Brand Name	Frequency, Route of Delivery, and Usual Dose
Avonex®	Flu-like symptoms following injection, which generally lessen over time. (See Managing Side Effects for more information.) Less common: depression, mild anemia, elevated liver enzymes, allergic reactions, heart problems.
Betaseron®	Flu-like symptoms following injection, which lessen over time for many. (See Managing Side Effects for more information.) Injection site reactions, about 5% of which need medical attention. Less common: allergic reactions, depression, elevated liver enzymes, low white blood cell counts.
Copaxone®	Injection site reactions. Less common: vasodilation (dilation of blood vessels); chest pain; a reaction immediately after injection, which includes anxiety, chest pain, palpitations, shortness of breath, and flushing (this lasts 15–30 minutes, passes without treatment, and has no known long-term effects).
Extavia®	Flu-like symptoms following injection, which lessen over time for many. (See Managing Side Effects for more information.) Injection site reactions, about 5% of which need medical attention. Less common: allergic reactions, depression, elevated liver enzymes, low white blood cell counts.
Rebif®	Flu-like symptoms following injection, which lessen over time for many. (See Managing Side Effects for more information.) Injection site reactions. Less common: Liver abnormalities, depression, allergic reactions, and low red or white blood cell counts.
Tysabri®	Headache, fatigue, urinary tract infections, depression, lower respiratory tract infections, joint pain, and chest discomfort. Less common: allergic or hypersensitivity reactions within 2 hours of infusion (dizziness, fever, rash, itching, nausea, flushing, low blood pressure, difficulty breathing, chest pain). (See Tysabri® Warnings on the next page.)
Immunosuppressant Drug	
Novantrone®	Blue-green urine 24 hours after administration; infections, bone marrow suppression (fatigue, bruising, low blood cell counts), nausea, hair thinning, bladder infections, mouth sores. Patients must be monitored for serious liver and heart damage. (See Novantrone® Warnings on the next page.)

Novantrone® Warnings

Novantrone® (mitoxantrone) is a chemotherapeutic drug, originally developed to treat certain forms of cancer. The total lifetime dose is limited in order to avoid possible heart damage. People taking Novantrone® should have tests of their heart function before each dose. It cannot be used in people with pre-existing heart problems, liver disease, and certain blood disorders. In addition to cardiac toxicity, acute myelogenous leukemia (AML), a type of cancer, has been reported in MS patients and cancer patients treated with Novantrone. AML can be fatal.

Tysabri® Warnings

Tysabri® slows or stops T cells from moving out of the bloodstream and into the brain and spinal cord where they may orchestrate the inflammation that is believed to result in MS attacks.

It is important that clients consider the following information in discussions with their healthcare professional about starting treatment with Tysabri. Individuals taking Tysabri are at increased risk for a rare, generally fatal brain disease called PML (progressive multifocal leukoencephalopathy), which is caused by the common JC virus. There are no interventions that are known to cure PML once it occurs, but a course of plasma exchange to remove Tysabri from the bloodstream as quickly as possible may provide benefit. Although the three cases of PML that occurred in the clinical trials were in patients who were also taking another immunomodulating or immunosuppressing medication, additional cases of PML in people who were not taking another immunomodulating or immunosuppressing medication at the same time have been reported in the post-marketing phase.

The absolute risk for PML in patients treated with Tysabri cannot be precisely estimated. However, the drug's sponsor has released data suggesting the risk increases with more time on therapy, starting out lower than the one-in-one thousand level that was estimated at the time of Tysabri's re-approval in 2006, and rising after two years of infusions to about one in one thousand. At this time, there is insufficient information to determine the risk of PML in those who have been on therapy for three years or more.

Because of the risk of PML, Tysabri is only available under a restricted distribution program referred to as the TOUCH™ program. Prescribing physicians, infusion centers, and patients must enroll in this mandatory registry program. Patients using Tysabri® should promptly report any continuously worsening symptoms that persist over several days to their prescriber.

Based on post-marketing experience with Tysabri, the FDA added an additional warning to the product's labeling information in February, 2008. Tysabri has been found to increase the risk of liver damage, even after a single dose. Any person who experiences symptoms of liver injury, including yellowing of the skin and eyes (jaundice), unusual darkening of the urine, nausea, feeling tired or weak, and vomiting, should contact his or her physician immediately. Blood tests can be done to check for liver damage.

Tysabri® should not be used by persons whose immune systems are weakened by disease or by the use of drugs that alter the immune system, including other disease-modifying MS therapies.

Currently, nothing is known about the safety of long-term use of Tysabri®—or whether additional side effects will emerge in time.

Warnings about IV Infusions

All drugs delivered by IV infusion pose risks of bruising, vein damage, blood clots and more. Infusions must be managed by a well-trained medical professional.

PAYING FOR A DISEASE-MODIFYING DRUG

The annual expense of these drugs is significant. At this writing not all health insurance plans include prescription drugs, although they will have to in the future in order to comply with federal standards as the 2010 federal health care reform law is implemented. However, even when prescription drug coverage is included in a health plan it does not assure that every drug is covered by the plan, and it is possible that some disease-modifying drugs are covered by a plan and some are not. Health plans typically have a list of specific drugs included in the plan known as a formulary or preferred drug list. The following table provides contact information for the patient assistance programs of the pharmaceutical companies that can provide consumers with reimbursement information and potential avenues to receive financial assistance with the cost of their drug.

Industry-Sponsored Sites for Patient Information and/or Financial Assistance		
Brand Name	Generic Name	Manufacturer/ Distributor and Year of FDA Approval
Immunomodulating Drugs		
Avonex®	Avonex Services: 800-456-2255	www.avonex.com www.msactivesource.com www.healthtalk.com
Betaseron®	BETAPLUS: 800-788-1467	www.betaseron.com www.betaseron.com/ patients/betaplus
Copaxone®	Shared Solutions: 800-887-8100	www.copaxone.com www.sharesolutions.com www.mswatch.com
Extavia®	Patient Services: 1-866-925-2333	www.extavia.com
Rebif®	MS LifeLines: 877-447-3243	www.rebif.com www.ms lifelines.com
Tysabri®	BiogenIdec Patient Services: 800-456-2255	www.tysabri.com
Immunosuppressant Drug		
Novantrone®	MS LifeLines: 877-447-3243	www.novantrone.com

Because Novantrone® and Tysabri® must be infused in a medical facility, they are covered under Medicare Part B. If Avonex® is administered in a physician's office or clinic, it will be covered by Medicare Part B.

Medicare Part D covers prescription drugs through private plans approved by Medicare. For more information on Medicare prescription drug coverage, go to:

www.nationalMSSociety.org/medicare_basics.asp, or call your chapter at 1-800-344-4867 for more information.

Medicaid includes prescription drug coverage. However, the list of specific drugs covered may vary from state to state. Contact must be made with a state's Medicaid office for details.

New Treatments on the Horizon

Several new oral therapies are expected to be available within the next few years. Clients can monitor the progress of these medications through the research pipeline and FDA approval process on the National MS Society's Web site (www.nationalMSSociety.org). As these oral medications become available, clients may want to talk with their physicians about the relative benefits and risks of starting or switching to one of them.

CATHETER CARE

The following is a detailed description of catheter care. This care requires a licensed nurse, or other properly trained person.

The mainstay of treating an atonic bladder or detrusor (bladder muscle)/ sphincter dyssynergia with elevated residual urine is intermittent clean catheterization. If an individual with one of these bladder problems or with frequent incontinence cannot perform clean intermittent catheterization because of insufficient manual dexterity, an indwelling intra-urethral or suprapubic catheter is indicated.

Should an indwelling catheter be necessary, a suprapubic tube should be considered as there is some evidence that there are fewer infections with this catheter. Many women with MS who require indwelling catheters are still menstruating or are incontinent of bowel which gives direct route of bacteria along the outside of the catheter into the bladder. The presence of recurrent urethritis or epididymitis and in severe instances, scrotal abscess in the male favors the use of a suprapubic catheter.

CARE OF THE INDWELLING CATHETER

- Routine care includes daily cleaning of the catheter and the urethral meatus which is where the catheter exits the body. There should be additional cleaning after bowel movements to prevent infection.
- Anti-microbial ointment at the catheter as it enters the meatus is not recommended, as this has not been shown to reduce infections.
- After routine cleaning care, secure catheter to leg with catheter strap or tape. This prevents the catheter from tugging, it prevents erosion of the urethra and it prevents the catheter from being pulled out.
- Keep the urine bag below the level of the bladder to prevent urine from flowing back into the bladder which can cause infection.

Assessing Bladder Drainage

If the level of urine in the bag has stopped rising (no urine has drained from the catheter in 6–8 hours):

- Check that the tubing is not twisted or kinked.
- Check that nothing is lying on the catheter.
- Check that the urine bag is below the level of the bladder.
- Check that clothing and/or bedding are not wet with urine.
- Check that pain or distention is not present
- If urine is leaking and wetting clothing/bed clothes, or if pain or lower abdominal distress is present, the catheter might need gentle irrigation (see below).

Draining the Leg Bag

- The drainage bag should be emptied at least every 8 hours or when the bag is 2/3 full.
- The draining spout and the non-sterile collecting container should not come into contact.
- Obtain urine specimens by sterile technique.

- After the bag is empty, clean the tip with betadine solution and then close the valve.
- Replace the drain spout into the sleeve on the bag.

Disconnecting the Leg Bag

- Do not disconnect the urine bag except to clean and put on a new bag.
- Before going to bed, change the leg bag used during the day to a larger night drainage bag.
- Make sure to empty the leg bag first before disconnecting.
- After the bag is empty, clamp the catheter by pinching the tubing.
- Clean the connection between catheter and tubing with betadine swab.
- Disconnect the catheter from the leg bag tubing and connect the night draining tubing to the catheter, then release the tubing.

Cleaning the Drainage Bag

- Unhook the old bag to be cleaned, and attach the Foley catheter to another drainage bag.
- Wash the old bag with soap and warm water, and then rinse the bag with warm water. Fill the bag with one part of white vinegar to three parts tap water. Let the bag sit with the water/vinegar mixture for 30 minutes. Empty the bag; rinse gently with water, and let air dry.
- There is little consensus as to how long to use a drainage bag. Recommendations vary from one week to one month. The drainage bag should be washed every day.

Changing the Catheter

- There is no uniform agreement on how often to change the catheter; once a month is usually recommended. For individuals not having any problem with the catheter, once every six weeks may be sufficient. With obstruction or infection it may be necessary to change the catheter as often as every one to three weeks. If the catheter is clogged, appears to be producing pain, or there is infection, then it may require immediate replacement.
- The most narrow, softest tube that will serve the purpose should be used. The usual size is French 14–16 with a 5 cc balloon inflated with 10 cc of water.

Fluid Intake

- The individual should drink enough fluid so that the urine is clear and pale yellow in color, at least 1.5–2 quarts of fluid a day.
- Carbonated drinks should be avoided as they make the urine alkaline, encouraging stone formation and bacterial growth.
- Bacterial growth may be deterred by acidic urine. Some have found it helpful to take cranberry extract in gel capsules to acidify the urine and keep bacteria from adhering to the bladder wall and thus causing infection. Cranberry extract gel capsules can be opened and the contents added to applesauce or other foodstuff. A client's physician should be advised if cranberry extract is being taken.
- Caffeine-containing beverages may irritate the bladder, increasing urgency and/or spasm.

Infection and Other Complications

There are always bacteria in the urine of someone with an indwelling catheter; this is not necessarily a true infection. Continuous use of antibiotics to prevent growth of asymptomatic bacteria in urine is rarely indicated and improper antibiotic use will lead to the growth of resistant bacteria which will be more difficult to treat and will eventually require more powerful antibiotics.

Signs of Urinary Tract Infection in an Individual With an Indwelling Urethral or Suprapubic Foley Catheter

- **Fever:** Fever greater than 101 degrees Fahrenheit may signify a kidney infection that requires immediate attention. A healthcare provider should be informed in case of any fever, however.
- **Nausea and vomiting** (This usually occurs with infection of the kidney)
- **Cloudy Urine:** If the urine becomes cloudy, blood tinged, shows a change with increased sediment and/or mucus, and/or has a foul smell, an infection may be present, but antibiotics may not be indicated. Start with increasing fluids for 24 hours and then if there is no improvement, antibiotics may be needed; inform a healthcare provider (nurse or physician) in any case.

- Colonization: An increase in the number of white blood cells in the urine (pyuria) is often a better indication of infection than is a culture which may reveal asymptomatic bacteria in the urine (colonization) or a significant infection. Use of urinalysis as well as culture and sensitivity are complimentary. The nature of the organism is also important in the decision of whether or not to treat (common contaminant versus serious pathogen).
- Sudden increase in physical weakness or fatigue
- Decreased mental acuity
- Hypotension
- More frequent blockage of the catheter
- Increased bladder spasms
- Lower abdominal pain and/or distention
- Increased spasticity

Treating Infection

- Make sure the catheter is draining well.
- Increase fluid intake, get urinalysis and urine culture and sensitivity as both may be necessary for subsequent selection of an appropriate antibiotic.
- The catheter should be changed when symptomatic urinary tract infection occurs and a urine specimen for culture and sensitivity and urinalysis should be taken once the new catheter is in place.
- Wash hands with soap and water before and after a urine specimen is obtained.

Most catheter-associated urinary tract infections that are asymptomatic are generally considered to be benign. These asymptomatic infections, with the exception of that associated with pyuria of significance, may not need treatment. Occasionally, especially when symptomatic, infection must be considered significant if symptoms persist more than a day. Such infection might lead to complications such as prostatitis, epididymitis, cystitis, pyelonephritis (or infection of the kidney), and bacteremia (sepsis) especially in high-risk individuals. Sepsis has a significant mortality; it occurs in less than 1% of catheterized individuals. The natural history of catheter-associated urinary tract infection is largely unstudied.

What to Do If Bladder Spasms Occur

- Spasms often present as leakage around the catheter.
- Anti-spasmodic (anticholinergic) medication is often of benefit: oxybutynin (Ditropan® 2.5–5 mg four times a day), flavoxate (Urispas® 100–200 mg four times a day), tolterodine (Detrol® 2 mg two times a day), or solifenacine succinate (Vesicare® 5 mg once daily).

Catheter Irrigation

- Catheter irrigation on a routine basis generally should be avoided. Irrigation once every two weeks or with a frequency as recommended by a physician might be of benefit if obstruction or plugging of the catheter is a recurring problem.
- Some physicians recommend sterile solution irrigants used with a large volume sterile syringe. Others recommend an acidic irrigation solution which might decrease the risk of infection as well decrease the clogging of the catheter.
- A 0.25% sterile acidic acetic acid solution is recommended by some physicians for bladder irrigation. The solution should not be kept for more than two weeks and should be refrigerated after it is made. The solution should be returned to room temperature before using.

BRADEN SCALE FOR PREDICTING PRESSURE

There are two versions of the Braden Scale, one for use in the hospital or nursing home setting, and one for use in home care. The latter is shown on the next two pages. Assessment with the home care version is recommended at the first visit and weekly for several weeks, then monthly if condition does not change. A videotape that teaches the use of the Scale is available for rent or purchase. For further information, contact Prevention Plus at 5102 Lafayette Avenue, Omaha, NE 68132; phone and fax 402-551-8636, www.bradenscale.com.

Braden Scale Evaluation Form

To obtain the Braden rating for an individual, add up all the factors for each parameter that apply to the individual. The lower the score, the higher the risk. (Indicatively, 20+ = low risk, 16 to 20 = medium risk, 11 to 15 = high risk, below 10 = high risk.)

Patient's Name	Evaluator's Name		Date of Assessment			

SENSORY PERCEPTION: Ability to Respond Meaningfully to Pressure-Related Discomfort

<p>1. Completely limited:</p> <p>Unresponsive (does not moan, flinch, or grasp) to painful stimuli, due to diminished level of consciousness or sedation,</p> <p>OR</p> <p>limited ability to feel pain over most of body surface.</p>	<p>2. Very limited:</p> <p>Responds only to painful stimuli. Cannot communicate discomfort except by moaning or restlessness,</p> <p>OR</p> <p>has a sensory impairment which limits the ability to feel pain or discomfort over 1/2 of body.</p>	<p>3. Slightly limited:</p> <p>Responds to verbal commands but cannot always communicate discomfort or need to be turned,</p> <p>OR</p> <p>has some sensory impairment which limits ability to feel pain or discomfort in 1 or 2 extremities.</p>	<p>4. No impairment:</p> <p>Responds to verbal commands. Has no sensory deficit that would limit ability to feel or voice pain or discomfort.</p>				
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MOISTURE: Degree to Which Skin Is Exposed to Moisture

<p>1. Constantly moist:</p> <p>Skin is kept moist almost constantly by perspiration, urine, etc. Dampness is detected every time patient is moved or turned.</p>	<p>2. Moist:</p> <p>Skin is often but not always moist. Linen must be changed at least once a shift.</p>	<p>3. Occasionally moist:</p> <p>Skin is occasionally moist, requiring an extra linen change approximately once a day.</p>	<p>4. Rarely moist:</p> <p>Skin is usually dry; linen requires changing only at routine intervals.</p>				
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Braden Scale Evaluation Form

ACTIVITY: Degree of Physical Activity

<p>1. Bedfast: Confined to bed.</p>	<p>2. Chairfast: Ability to walk severely limited or nonexistent. Cannot bear own weight and/or must be assisted into chair or wheel chair.</p>	<p>3. Walks occasionally: Walks occasionally during day but for very short distances, with or without assistance. Spends majority of each shift in bed or chair.</p>	<p>4. Walks frequently: Walks outside the room at least twice a day and inside room at least once every 2 hours during waking hours.</p>				
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MOBILITY: Ability to Change and Control Body Position

<p>1. Completely immobile: Does not make even slight changes in body or extremity position without assistance.</p>	<p>2. Very limited: Makes occasional slight changes in body or extremity position but unable to make frequent or significant changes independently.</p>	<p>3. Slightly limited: Makes frequent though slight changes in body or extremity position independently.</p>	<p>4. No limitations: Makes major and frequent changes in position without assistance.</p>				
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Braden Scale Evaluation Form

NUTRITION: Usual Food Intake Pattern

1. Very poor:	2. Probably inadequate:	3. Adequate:	4. Excellent:				
<p>Never eats a complete meal. Rarely eats more than 1/3 of any food offered. Eats 2 servings or less of protein (meat or dairy products) per day. Takes fluids poorly. Does not take a liquid dietary supplement,</p> <p>OR</p> <p>is NPO [1] and/or maintained on clear liquids or IV [2] for more than 5 days.</p>	<p>Rarely eats a complete meal and generally eats only about 1/2 of any food offered. Protein intake includes only 3 servings of meat or dairy products per day. Occasionally will take a dietary supplement,</p> <p>OR</p> <p>receives less than optimum amount of liquid diet or tube feeding.</p>	<p>Eats over half of most meals. Eats a total of 4 servings of protein (meat, dairy products) each day. Occasionally will refuse a meal, but will usually take a supplement if offered,</p> <p>OR</p> <p>is on a tube feeding or TPN [3] regimen, which probably meets most of nutritional needs.</p>	<p>Eats most of every meal. Never refuses a meal. Usually eats a total of 4 or more servings of meat and dairy products. Occasionally eats between meals. Does not require</p>				

Braden Scale Evaluation Form

FRICTION AND SHEAR

<p>1. Problem:</p> <p>Requires moderate to maximum assistance in moving. Complete lifting without sliding against sheets is impossible. Frequently slides down in bed or chair, requiring frequent repositioning with maximum assistance. Spasticity, contractures, or agitation leads to almost constant friction.</p>	<p>2. Potential problem:</p> <p>Moves feebly or requires minimum assistance. During a move skin probably slides to some extent against sheets, chair, restraints, or other devices. Maintains relatively good position in chair or bed most of the time but occasionally slides down.</p>	<p>3. No apparent problem:</p> <p>Moves in bed and in chair independently and has sufficient muscle strength to lift up completely during move. Maintains good position in bed or chair at all times.</p>					
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TOTAL SCORE:

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INTRATHECAL BACLOFEN THERAPY

Intrathecal baclofen therapy is an intervention used by many people with multiple sclerosis to address severe spasticity.

What is baclofen?

Baclofen is a muscle relaxant medicine commonly used to decrease spasticity related to multiple sclerosis, spinal cord injuries, or other neurological diseases. Spasticity is a motor disorder characterized by tight or stiff muscles that might interfere with voluntary muscle movements.

How does baclofen work?

Spasticity is caused by an imbalance of excitatory and inhibitory input in the spinal cord. This imbalance causes hyperactive muscle stretch reflexes. These reflexes result in involuntary spasms and increased muscle tone. Baclofen works by restoring the balance of excitatory and inhibitory input to reduce muscle hyperactivity. In this way, it allows more normal motor movements.

How does Intrathecal Baclofen Therapy (ITB) work?

Intrathecal Baclofen Therapy is a treatment option that delivers an injectable form of baclofen, Lioresal Intrathecal (baclofen injection), directly to the fluid surrounding the spinal cord by using a programmable pump and catheter that are surgically placed in the body. This method of drug delivery is called intrathecal infusion. The drug infusion system delivers the medication in small, precisely controlled doses. What makes ITB therapy different from oral medications is the delivery of the drug baclofen to the fluid-filled area surrounding the spinal cord, called the intrathecal space. Unlike oral medications, which circulate throughout the body in the blood, the drug is delivered where it is used. This may help minimize potential systemic side effects.

What are the side effects?

Oral and intrathecal baclofen can cause potential side effects. Some side effects of baclofen include dizziness, drowsiness, headaches, nausea, and weakness.

Why might intrathecal baclofen be preferred over oral baclofen?

Baclofen can be taken orally or delivered into the intrathecal space. The intrathecal space contains the cerebrospinal fluid, the fluid surrounding the spinal cord and nerve roots. Oral baclofen causes side effects that might limit its usefulness.

Of the oral baclofen delivered throughout the body only a small portion goes to the spinal fluid where it is needed to work. An intrathecal delivery system, which provides the baclofen right to the target site in the spinal cord, is an effective way to deliver the medicine.

What is the baclofen pump system?

The baclofen pump system is the intrathecal (directly into the spinal fluid) method of delivering the medicine. The system consists of a catheter (a small, flexible tube) and a pump. The pump—a round metal disc, about one inch thick and three inches in diameter—is surgically placed under the skin of the abdomen near the waistline.

The pump stores and releases prescribed amounts of medicine through the catheter. The pump is refilled by inserting a needle through the skin into a filling port in the center of the pump. With a programmable pump, a tiny motor moves the medicine from the pump reservoir through the catheter. Using an external programmer, the treatment team can make adjustments in the dose, rate, and timing of the medicine.

Patients must return to their doctor's office for pump refills and medicine adjustments, typically every two to three months. The pump is taken out and replaced at the end of the battery's life span, which is usually five to seven years.

Who is a candidate for the pump system?

Anyone who has spasticity and is not responsive to oral medicine can be considered for the baclofen pump system.

What are the advantages of the baclofen pump system?

- It efficiently reduces spasticity and involuntary spasms, promoting a more active lifestyle, better sleep, and reduced need for oral medicines.
- It continuously delivers baclofen in small doses directly to the spinal fluid, increasing the therapeutic benefits, and causing fewer and less severe side effects compared to the oral medicine.
- It can be individually adjusted to allow infusion rates that vary over a 24-hour period.

- It can be turned off if spasticity reduction has shown no benefit.
- Pain and discomfort from spasms and spasticity are often reduced or eliminated.

What is involved in the initial evaluation for baclofen therapy?

If a person with MS is considering intrathecal baclofen therapy, he/she will likely have an initial evaluation by a treatment team that might include a doctor who specializes in rehabilitation (physiatrist), a physical therapist, an occupational therapist, a nurse, and a social worker. All of these professionals work as a team to provide a comprehensive evaluation of spasticity symptoms and establish a treatment plan adapted to a patient's personal needs.

How will a doctor know if the baclofen pump system will work?

If the treatment team recommends the baclofen pump system after an evaluation, the patient will have a trial of the intraspinal therapy to test the potential effectiveness of the medicine.

During the medicine trial, baclofen is injected into the spinal canal (using a small needle) and the patient is assessed by the treatment team over two to four hours to determine how well the medicine treats the spasticity. If muscles don't relax during the first trial, a larger dose might be given on a later date to determine its effectiveness. Patients who experience positive results with the intrathecal medicine can decide with their doctor and family members if they should have a baclofen pump system implanted.

What happens after the surgical procedure?

After the implantation procedure, the patient stays in the hospital a few days so recovery can be closely monitored. While in the hospital, the dose of baclofen is adjusted. Follow-up visits with the doctor are scheduled.

How does one know when the battery in the pump is about to run out?

The pump is equipped with an alarm that beeps when the battery is near depletion. The alarm is a soft, high-pitched beep. The beeps may occur several times a minute. The alarm is designed to alert the patient and doctor that the pump should be checked.

The doctor can program an alarm “test” during an office visit so that the patient can hear what the alarm sounds like. The pump alarm is a relatively soft beep; as a result, some people have trouble hearing it when the pump is implanted. Because the patient may not be able to hear the soft alarm, the doctor should be contacted if the patient experiences a change in his/her condition.

If the low-battery alarm is sounding, how long will it be before the battery is fully depleted?

Many people are surprised at how soft the alarm is and may not hear it when it initially starts. Other times, the person does not hear it at all. For this reason, it is recommended that the patient schedule a pump replacement as soon as a low-battery alarm is confirmed by the doctor. If this is not possible, the doctor may prescribe oral medications as a precaution. The oral medication may supplement other medical treatment and is meant to help prevent withdrawal symptoms in the event that the pump stops working before it is replaced.

Does the alarm always indicate a battery nearing depletion?

No. The pump alarm may indicate that the pump needs refilling or that there is a pump memory error (see next page). If the pump needs refilling, a “low-reservoir” alarm will sound. The alarm also may temporarily sound if the drug was not warmed to body temperature before the pump was filled. This alarm is a single beep. If the alarm sounds for more than a few minutes, the patient should call the doctor to identify and correct the situation. During the clinic visit, the doctor will check the pump and manage any problems.

Is there an alarm to indicate that there is a problem with the pump?

Yes. There is a pump memory alarm. If there is a pump memory error, the pump will sound a double-beep alarm. A pump memory error may occur if the pump memory is compromised by a strong magnetic force or other circumstances (such as an MRI exam).

Once activated, each alarm occurs at specific intervals until the doctor shuts the alarm off with the physician programmer. Under certain circumstances the pump alarm may sound intermittently. This could indicate that the battery is nearing depletion. If an intermittent alarm occurs, client should contact the doctor immediately.

EMERGENCY PREPAREDNESS

It is important that a person with a disability who is living at home have particular procedures and plans in place in the event of a natural disaster or emergency. The following provides more detailed information and recommendations about such preparations.

EMERGENCY PREPAREDNESS KITS

Essential Supplies Needed by Everyone

- Emergency Contact List—including a contact person at least 100 miles from individual's location. List Emergency Support Network names and telephone numbers.
- Medical Information List—list medical conditions, impairments/limitations, blood type, medical providers, medications, special equipment and supplies needed, vendors' phone numbers, special care instructions, health insurance information.
- Two weeks of medications, extra copies of medication prescriptions.
- Important Documents kept in a waterproof freezer bag—copy of will, insurance documents, deeds, assets, bank and charge account numbers, birth and/or marriage certificate, social security cards and award letters, etc.

Mobile Emergency Disaster Kit

In addition to Essential Supplies listed on the previous page:

- Flashlight
- Battery-powered radio
- Batteries
- Whistle
- Light sticks
- Water (2 quarts)
- Clothing change
- Emergency blanket
- Food bars
- Rain poncho
- First aid kit (can purchase from American Red Cross with backpack)
- Breathing mask
- Map (for locating shelters)
- Cash

Emergency Disaster Kit for Remaining In Place

In addition to Essential Supplies listed on the previous page:

- Battery-powered radio
- Flashlight
- Extra batteries
- Water (at least three gallons per person)
- Minimum of three days non-perishable food supply per person
- First aid kit
- Extra pair of glasses
- Sanitation supplies—toilet paper, diapers, soap, plastic garbage bags
- Disinfectant
- Paper goods such as plates, cups, eating utensils
- One complete change of clothing and footwear per person, thermal underwear, rain gear
- Blankets
- Tools and supplies such as plastic sheeting, duct tape, work gloves, signal flares, paper and pencil, disposable dust masks, whistle, light flares
- Map (for locating shelters)
- Cash

SPECIAL NEEDS

Visual Impairment

If the individual has a visual impairment, he/she should:

- Mark disaster supplies and emergency shut-offs with fluorescent color-coded tape, large print or Braille.
- Have an extra magnifier.
- Place security lights in each room to lead to exit. These lights plug into electrical wall outlets and light up automatically even if electricity is lost.
- Have high-powered flashlights with wide beams.
- Have extra glasses.
- Have an extra white cane, if used.
- Store a talking clock or large-print timepiece with extra batteries.

Hearing Loss

If the individual has a hearing loss, he/she should:

- Obtain a small portable battery-operated television set that provides open-captioning or sign-language. Determine which broadcasting systems offer access to captioned and/or signed emergency information.
- Keep pads and pencils in their mobile and home emergency kits.
- Keep a card at all times that informs others of his/her hearing loss and communication modes.
- Have a whistle and pad and pencil by his or her bed.
- Keep a page of key emergency signs/translations with disaster kit to share with emergency personnel if needed. (See example on American Red Cross website.)
- Have extra hearing aid batteries on hand.
- Make sure that both audible and visual smoke alarms are installed and working.

Speech or Communication Impairment

If the individual has a speech or communication impairment, he/she should:

- Consider buying a power converter to be able to operate a laptop from a car cigarette lighter.
- Have a paper and pencil at all times to be able to communicate.
- Keep copies of a word or letter board or key phrase cards in all disaster kits to permit communication with emergency personnel. (See example on American Red Cross website.)

Cognitive Disability

If the individual has a cognitive disability, he/she should:

- Have a clear and easy-to-follow emergency plan.
- Carry a pen and pencil at all times in case he/she need to write instructions down.

Resources

Additional recommendations for emergency preparedness can be found on the following websites:

- <http://www.redcross.org/services/disaster/beprepared/>
- <http://www.preparenow.org/eqtips.html>
- <http://www.disabilitypreparedness.org>
- <http://www.nod.org>

FINANCIAL ASPECTS OF IN HOME CARE

There are numerous sources for financial assistance to assist with the costs associated with in-home care.

The most common ways to pay for home care are:

- Personal and family resources
- Private health insurance
- Long-term care insurance
- Medicare, Medicaid, Department of Veteran Affairs, and Title programs
- Community-based service programs

To determine eligibility for financial assistance, families should complete a full assessment of their financial resources. Important steps to follow are:

- Identify current assets, sources of income, and insurance entitlements.
- Prepare a budget and make projections of future income from all sources.
- Confirm the retirement benefits of the person receiving your care.
- Estimate the expenses of professional care, equipment, out of pocket medical expenses, and any medical procedures that may be needed.
- Determine what care items and expenses are tax-deductible.
- Determine if the person's health insurance policy has home healthcare benefits.

Eligibility for public pay programs (Medicare, Medicaid, and Department of Veteran Affairs) should be discussed with an appropriate representative from these organizations. Some states have long-term care and/or personal-care assistant programs for people who are not traditionally eligible for Medicaid.

As a general rule, persons with MS are ineligible to purchase long-term care insurance once a diagnosis has been made. However, if there is a policy in place, this could be a resource for payment.

Who Can Assist in Identifying Potential Resources?

Families should begin by talking with staff of the National Multiple Sclerosis Society or with a social worker at the local hospital, social agency, or MS clinic.

Care managers can be most helpful by linking families to services and entitlements in the community. These professionals, usually a social worker or a nurse, are skilled in exploring eligibility for financial assistance to cover home health services and will consult with other professionals to determine what assistive devices, home modifications, or housing alternatives are needed. Care managers can explore transportation resources and options, refer for individual or family counseling, and provide on-going support. They can be very effective advocates on behalf of clients.

Home health care is covered by a number of payers, including traditional Medicare, Medicare Advantage, Medicaid, the Veterans' Administration, TRICARE, the Federal Employees Health Benefits Program, Older Americans Act programs, private insurance, and private pay. Medicare is currently the largest payer of home health services, with Medicaid increasingly oriented towards rebalancing resources between institutional and home and community based services, including personal care services designed to prevent nursing home placement.

Medicare Coverage for Home Health Care

There is no legal limit on the duration of time for which home health coverage is available. Further, Medicare covers home health services in full, with no required deductible or co-payments from the beneficiary. Services must be medically necessary and reasonable and the following criteria must be met:

- A physician has signed or will sign a plan of care.
- The patient is or will be homebound. This criterion is met if leaving home requires a considerable and taxing effort which may be shown by the patient needing personal assistance, or the help of a wheelchair or crutches, etc. • The patient needs or will need physical or speech therapy, or intermittent skilled nursing (from once a day for periods of 21 days at a time if there is a predictable end to the need for daily nursing care, to once every 60 days).
- The home health care is provided by, or under arrangement with, a Medicare-certified provider.

If the triggering conditions described above are met, the beneficiary is entitled to Medicare coverage for home health services. Home health services include:

- Part-time or intermittent nursing care
- Physical, occupational, or speech therapy
- Medical social services under the direction of a physician
- To the extent permitted in regulations, part-time or intermittent services of a home health aide

The Balanced Budget Act of 1997 made significant revisions to the Medicare home health benefit (BBA). These changes apply to services provided on or after January 1, 1998. While the BBA did not change the Medicare home health coverage criteria, the changes did alter the payment structure and, in practice, this change resulted in reduction in services, particularly for individuals in need of long term or extensive care. Denials of Medicare home health coverage should not be predicated upon particular diagnoses or the fact that a patient's condition is chronic or unlikely to improve. Each patient should be provided with an individualized assessment of his or her right to coverage in light of the qualifying criteria. Remember:

- Medicare coverage should not be denied simply because the patient's condition is "chronic" or stable." "Restorative potential" is not necessary.
- Resist arbitrary caps on coverage such as " aide services in excess of one visit per day are not covered", or that "daily nursing visits can never be covered."
- There is no legal limit to the duration of the Medicare home health benefit. Medicare coverage is available for necessary home care even if it is to extend over a long period of time.
- The doctor is the patient's most important ally. If it appears that Medicare coverage will be denied, the doctor needs to help demonstrate that the standards above are met. Home care services should not be ended or reduced unless the doctor has ordered it.
- In order to be able to appeal a Medicare denial, the home health agency must have filed a Medicare claim for the patient's care, even if the agency expects that Medicare will deny coverage.

Medicare home health care is not intended as only a short term benefit for those with acute conditions. According to CMS's Home Health Manual, HIM-11, 205.1, "The determination of whether an individual needs skilled nursing care should be based solely upon the individual's unique condition and individual needs, without regard to whether the illness or injury is acute, chronic, terminal or expected to extend over a long period of time. In addition, skilled care may, dependent upon the unique condition of the individual, continue to be necessary for individuals whose condition is stable."

Medicare provides the following illustration of the above policy:

“An individual with advanced multiple sclerosis undergoing an exacerbation of the illness needs skilled teaching of medications, measures to overcome urinary retention, and the establishment of a program designed to minimize the adverse impact of the exacerbation. The skilled nursing care the individual needs for a short period would be covered despite the chronic nature of the illness.”

According to Medicare, skilled nursing visits can also be reasonable and necessary in the following circumstances:

- **Observation and assessment** of an individual’s condition when only the specialized skills of a healthcare professional can: (1) determine an individual’s status and the potential for a change in condition, and (2) evaluate the need for possible modifications of treatment or the need for new services until the individual is stable.
- **Teaching and training** activities requiring a skilled nurse to teach an individual, family member, or caregiver how to manage the beneficiary’s course of treatment, unless it becomes apparent that he/she is not willing or capable of being trained.
- **Management and evaluation** of an individual Plan of Care where the individual’s condition or complications require the services of a skilled nurse to ensure that non-skilled care, e.g., home health aide services, is achieving its purpose.

THE NEED FOR REHABILITATION IN MS

Rehabilitation in MS is a process that helps a person achieve and maintain maximal physical, psychological, social and vocational potential, and quality of life. Achievement and maintenance of optimal function are essential in a progressive disease such as MS.

Rehabilitation is considered a necessary component of comprehensive, quality health care for people with MS at all stages of the disease. A growing body of evidence indicates that improvement in mobility, activities of daily living, quality of life, prevention of complications, and increased safety and independence may be realized by a carefully planned program of exercise, functional training, and activities that address the specific needs of the individual.

Third party reimbursement can be difficult to obtain for people with MS, as insurers are often looking to restoration and improvement as the rationale for coverage of rehabilitation services. Yet, for people with MS, maintaining functioning, or slowing deterioration of functioning, are just as important.

In order to help clinicians better advocate for patients with MS seeking rehabilitation therapies, the National Multiple Sclerosis Society has developed a tool kit of appeal letters and citations to assist physicians in the appeal process. The following is a template letter that physicians can use in their appeal for physical rehabilitation. Copies of the citations cited in the letter can be obtained by contacting the Professional Resource Center of the Society at healthprof_info@nmss.org.

Model Appeal Letter—Rehabilitation/Physical Therapy

Today's date

Plan Name

Plan Address

Plan Address

Re: Client's name, Insurance ID # (and claim # if applicable)

To Whom It May Concern:

This is a request for (**prior authorization, continuation of benefits, appeal of your denial**) for physical rehabilitation for my patient _____(**name**)_____, who lives with multiple sclerosis. I prescribed a medically necessary program of (**inpatient or outpatient**) physical rehabilitation to enable her/him to achieve and maintain optimal functioning.

A thorough physical therapy evaluation and development of a treatment plan by an appropriately skilled therapist is needed at this time (**fill in specific details of short and long-term treatment goals, e.g., to regain as much functioning as possible following an exacerbation, for symptom management, to develop risk reduction strategies in the home, other—site functional limitations, ADLs/IADLs, etc.**).

The National Multiple Sclerosis Society defines rehabilitation as “a process that helps a person achieve and maintain maximal physical, psychological, social and vocational potential, and quality of life consistent with physiological impairment, environment, and life goals”. Further, the Society’s clinical guidelines assert that rehabilitation is an essential part of the management of MS, including the reduction of risk (see enclosed). The goal is to establish corrective exercises and activity programs that are appropriate, realistic, and meaningful, with a strong focus on improving and maintaining function.

The effectiveness of physical therapy in the MS population has been demonstrated. In 2008 Khan and colleagues reported MS patients randomized to individualized rehabilitation showed reduced disability and statistically significant differences in post-treatment Functional Independence Measure (FIM) scores, compared to the non-treatment group.

A study on risk of falls among persons with MS concluded “assessment of different aspects of motor impairment and the accurate determination of factors contributing to falls are necessary for individual patient management and therapy for the development of a prevention program for falls”.

Sincerely,

John Smith, MD

cc. (patient's name)

The National Multiple Sclerosis Society has several client booklets focused on MS and rehabilitation including:

- ***Exercise as Part of Everyday Life***
- ***Managing MS Through Rehabilitation***
- ***Stretching for People with MS***
- ***Stretching with a Helper for People with MS***
- ***Controlling Spasticity in MS***
- ***Fatigue: What You Should Know***
- ***Gait or Walking Problems: The Basic Facts***
- ***Speech and Swallowing: The Basic Facts***
- ***Tremor: The Basic Facts***

Visit nationalmssociety.org/brochures to download, or call your chapter at 1-800-344-4867 to have copies mailed to you.

RESOURCES

The National Multiple Sclerosis Society

National Multiple Sclerosis Society (733 Third Avenue, New York, NY 10017; tel: 800-344-4867; nationalMSSociety.org). The National MS Society helps each person address the challenges of living with MS through our 50-state network of chapters. The Society helps by funding cutting-edge research, driving change through advocacy, facilitating professional education and providing programs and services that help people with MS and their families move their lives forward. The Society's goals include provision of nationwide services to assist people with MS and their families, and provision of information to those with MS, their families, professionals, and the public. The programs and services of the Society promote knowledge, health, and independence while providing education and emotional support.

- Toll-free access to local resources by calling 1-800-344-4864 for up-to-date information and referrals.
- Website with updated information and educational programs, for lay audiences and professionals, related to treatments, research, and programs. nationalMSSociety.org, for the national site. Additionally, many chapters maintain websites for their service areas.
- Professional Resource Center (email: MD_info@nmss.org, HealthProf_info@nmss.org) for healthcare professionals involved in the care of people with MS and their families. nationalMSSociety.org/PRC
- Professional Information and Library Services – information about MS and its management, access to the largest collection of MS-related materials available in a single site, and library/literature search services.
- Information about insurance and long-term care for people with MS.
- Continuing education programs.
- Consultation on the development of National MS Society-affiliated clinical facilities.
- Knowledge Is Power self-study program (serial mailings) for people newly diagnosed with MS and their families.
- MS Learn Online, an online education series for people with MS and their families, available on the National MS Society website.
- Printed materials available on a variety of topics.
- Educational programs on various topics throughout the year, provided at chapters around the country.
- Annual national teleconference at over 500 sites throughout the United States; call 1-800-344-4864 for the location nearest you.
- Wellness programs

Programs Offered by the National MS Society

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.

Professional Resource Center

The Professional Resource Center (PRC) is a comprehensive resource for health care professionals offering information, continuing education, consultation with multidisciplinary experts and publications. The PRC houses the most comprehensive library of MS information in the world and hosts a comprehensive 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.

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. **nationalMSSociety.org**
- **The Professional Resource Center:** This center provides information and multidisciplinary expertise about MS and its management to healthcare professionals; it is supported by the National MS Society. **nationalmssociety.org/PRC**
- **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.mscares.org
- **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

Accessibility, Assistive Technology, and 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 and 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 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.disabilityinfo.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

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



**National
Multiple Sclerosis
Society**

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Professional Resource Center