

# Serving Individuals with Multiple Sclerosis in the Home:

## Guidelines & Recommendations for 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 healthcare professionals specializing in the care of people with multiple sclerosis. It is intended to provide a guide for serving people with MS in a 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 with multiple sclerosis (MS). It can provide guidance to administrators and staff of home care agencies seeking to develop effective care plans for clients with MS. It can serve as a resource to home care nurses, home health aides, personal care attendants, in-home respite workers, private duty nurses, and others who want to learn more about the disease in order 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 with MS. Consistent with this responsibility, the Society brought together an expert panel of National MS Society staff and MS 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 personal care and other services at home. This task force, which also included people with MS and caregivers, contributed knowledge and clinical expertise to the preparation of this document through a series of meetings and discussion of best practices.

## **HOME HEALTH CARE FOR INDIVIDUALS 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 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 healthcare 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 in nursing home facilities. 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 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 than the elderly—work, primary financial security, familial role and role relationships, ability to actively parent, and loss of or diminished sexual functioning.

## **Client Profiles**

Here are the stories of two people 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 became worse 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 had 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, making transfers a challenge and is dependent for all activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs include walking, bathing, dressing, grooming, transferring, toileting, etc. IADLs refer to activities such as meal preparation, laundry, check writing, grocery shopping, etc. He receives Medicaid and SSI for personal care assistance through his state's Medicaid personal care assistant (PCA) program. He receives 8 hours of care each day, including weekends, of personal care and IADL assistance 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. His personal assistants, by helping him manage medical and personal care needs, help him 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 activities of daily living (ADLs) and instrumental activities of daily living (IADLs).
- The person with MS has experienced a recent hospitalization and is recuperating from an acute episode.
- There has been a recent loss of a caregiver (through death, separation or divorce, marriage, 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.
- There has been a decrease in the person's motivation or there is poor compliance with medical/nursing/rehab care.
- The caregiver/spouse/family members 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".
- The person and/or the home situation is deteriorating visibly—poor personal hygiene, person appears disheveled, noticeable weight loss or gain, house is unkempt or dirty, etc.
- The individual has been discharged from an acute care setting with significant medical needs.

## 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 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. The potential for these complex relationship issues is not usually significant in the elderly population. 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 principal physician is not usually a team member

but instead acts as consultant. A nurse or social worker acts as 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 own defense system attacks and damages myelin, the insulating material that surrounds and protects the nerve fibers of the brain and spinal cord. There is now strong evidence that these nerve fibers are also damaged in MS. Damage to nerve pathways and damage to their myelin sheaths causes the symptoms of MS. This damage to the myelin and the nerve fibers forms hardened "plaques," and these hardened, or "sclerotic" areas scattered throughout the brain and spinal cord gave rise to the name, multiple sclerosis. When any part of the myelin sheath or nerve fiber is damaged or destroyed, nerve impulses to and from the brain are distorted or interrupted. MS is not contagious 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 with MS, intellect is preserved. MS also causes mood swings and depression (one study indicated that the risk of suicide in the MS population may be seven times that of the general population). Symptoms vary greatly in type and severity from one person to another and may come and go unpredictably.

## **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. Today, six medications approved by the Food & Drug Administration (FDA)—interferon beta 1-a (Avonex), interferon beta 1-b (Betaseron), glatiramer acetate (Copaxone), interferon beta 1-a (Rebif), mitoxantrone (Novantrone) and natalizumab (Tysabri)—reduce the frequency and severity of attacks of MS and/or may delay or slow down progression of the disease. *Appendix A includes additional information on these six MS medications.*

Many medications are available to reduce some of the symptoms of MS, and many other drug therapies are being clinically tested. Either intravenous or oral steroid administration is a method of choice for management 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 may be effective for 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, good general and 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 with progressive disability, there is 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, too, as the ability to move about the community and engage in social interactions is diminished. Cognitive changes may 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 in about 5–7% of persons with MS.

# Clinical Issues and Symptom Management

While some of the 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 may be addressed and to describe the range of clinical experiences common to those with MS. It is not assumed that these interventions will necessarily be provided by the home care staff.*

**Key to the Icons:** Topics of discussion are identified by icons as follows:

|                               |   |   |                                  |
|-------------------------------|---|---|----------------------------------|
| What Is It?                   |  |  | Interventions:<br>Medications    |
| Psychosocial<br>Impact        |  |  | Interventions:<br>Rehabilitation |
| Interventions:<br>Strategies  |  |  | Interventions:<br>Equipment      |
| Interventions:<br>Environment |  |  | Interventions:<br>Surgical       |

## Balance Problems



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



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.



A cane or other assistive mobility device may 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 unsteadiness. If walking remains extremely difficult or impossible despite devices, a wheelchair may be the correct choice to compensate for impaired balance and mobility.

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





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. Often a therapist can 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 may provide safe and independent mobility and canes or walkers can 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, which include 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



Bladder dysfunction is very common in MS and may 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.



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.



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.



Medications such as oxybutynin (Ditropan), 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 may help relieve retention, or the bladder's difficulty releasing urine: hyoscyamine (Levsinex, Levbid, Cystospaz), and flavoxate (Urispas).



Some individuals with MS may elect surgical procedures to manage continence. 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.

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

## 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, may 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. Suggesting the use of 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 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.

**Constipation:** Constipation may be due to anal or pelvic floor muscle spasticity, decreased sensation or muscle weakness. Also, MS involvement of the bowel, which causes slow transit of food stuffs through the bowel, and increased water absorption, may 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.



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.



When necessary, mild stimulants might be added (e.g., milk of magnesia). Glycerin suppositories provide lubrication as do theravac mini-enemas that are not really enemas but rather 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 and should be used only when nothing else works. These may cause bowel dependence. They are, however, necessary for optimal scheduling of activities when suppositories do not work and therefore maybe 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 over use 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.



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

## Cognitive Changes



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, 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.



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.



The use of compensatory strategies may be helpful to minimize the impact of these deficits. Repeat information and write down important points. Follow up verbal instructions with written back up and use visual aids when possible. Encourage the person to keep a notebook, electronic organizer, or calendar to track important information.



For an individual with MS, impairment of judgment, planning, and organizational function may have an impact on the safety of operating wheelchairs, especially power-operated wheelchairs or scooters. An occupational therapist should be consulted to address issues of safe driving (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 may 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 may 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 may improve with management of an MS relapse and may 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.

## Dysphagia (Swallowing Difficulties)



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



Eating is often a social activity involving family and friends. Swallowing problems may 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.



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 may 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.



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 which includes usually a modified Barium swallow test performed under fluoroscopy in the x-ray department; and (2) swallow “therapy”. See the section on Respiratory Muscle Weakness (pages 24–25) for additional information and recommendations.



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.

*(see TIPS for dealing with dysphagia on the next page)*



### TIPS: Dysphagia (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. Persons identified with swallowing problems should be instructed in the self-Heimlich procedure.
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 that 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.

### Fatigue



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 may 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 may 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 may be worsened by exposure to heat (as with a hot shower, hot bath, heated swimming pool, or electric blanket).



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.



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.



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, have an effect on motor fatigue.



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 deconditioning adds to fatigue and muscle atrophy. Exercise is important to combat both.

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

## 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 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



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.



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.



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.

*(see TIPS for dealing with hearing loss on the next page)*

### 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.

\*[http://www.healthinaging.org/agingintheknow/chapters\\_ch\\_trial.asp?ch=25](http://www.healthinaging.org/agingintheknow/chapters_ch_trial.asp?ch=25)



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 so doing, 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 may result in overuse of the upper limbs that, in turn, may 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 may produce painful spasms (see section on Spasticity, pages 30–32). Also, sensory disturbances may be painful. They may be perceived as a burning feeling, painful pins and needles or other unpleasant sensations.



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



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.



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 musculo-skeletal 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



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 and 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.



It is advised that the individual limit exposure to others with upper respiratory infections, which 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.



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, 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.



A Mechanical Insufflation-Exsufflation (MI-E) device, used with a facemask or mouthpiece, clears retained broncho-pulmonary 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 may 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



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).



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.



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



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, may 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, and in an abdominal fold) and being underweight in which condition, more 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; these include diabetes and anemia. Mental confusion is a risk factor also in that if one cannot be 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.*



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.



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 box on the next page for recommendations on how to prevent pressure sores.



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.
  - Cushions of foam, gel, or air to relieve pressure are of benefit, as is proper seating and positioning. Donut-shaped cushions are to be avoided. Skin should be protected from injury. The skin over bony parts of the body should not be massaged. Friction should be avoided on re-positioning. A thin area of cornstarch to areas vulnerable with regard to friction might be applied. Incontinence must be managed and meticulous hygiene maintained.
  - 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



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.



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.



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 use of medication. Techniques such as intermittent catheterization or medication can control urinary leakage during intercourse.



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, which 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.

*(see TIPS for dealing with sexual dysfunction on the next page)*

## 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 for more information.

## Spasticity



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.



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



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.



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 extremity, 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 is important.

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.



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.

*(see TIPS for dealing with spasticity on the next page)*

## 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



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.



Reduced ability to communicate effectively can have 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.



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.

## Tremor



Tremor, or involuntary shaking, can be very disabling for people with MS when it affects the limbs or head. Tremor, which appears with use of a limb, is referred to as intention 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.



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



Drugs such as hydroxyzine (Vistaril, Atarax), clonazepam (Klonopin), propranolol (Inderal), primidone (Mysolin), isoniazid (INH), and topiramate (Topamax) may help reduce tremor but only with very limited success. Physical techniques, e.g., weighting, immobilization, icing, and patterning, may help. Tremors are very challenging to control. Severe cases of tremor may be amenable to surgical procedures; however, these procedures carry considerable risk.



Weights and other devices can be attached to a limb to inhibit or compensate for tremors. An occupational therapist is the health professional that can best advise about assistive devices to aid in the management of tremor. Speech therapy may help control tremors of the lips, tongue, and jaw.

### TIPS: Tremor

1. Handrails and grab bars strategically placed may provide safe and independent mobility.
2. Weighted utensils or wrist weights may reduce tremor enough for the individual to carry out some ADLs.
3. Stabilizing the limb, for example stabilizing the elbows on the table, may reduce tremor in the wrist and hands.

### Vision Deficits



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.



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.





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



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.



Reduced mobility secondary to weakness, may significantly impair the 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.



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 the 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.

*(see TIPS for dealing with weakness on the next page)*

### 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 pages 53–54 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.