

MULTIPLE SCLEROSIS SYSTEM OF CARE PROCEDURES

- 1. REASON FOR ISSUE.** This Veterans Health Administration (VHA) Handbook establishes policy and procedures for health care services for Veterans with multiple sclerosis (MS). It describes the essential components and procedures of the MS program that are to be implemented nationally to ensure that all enrolled Veterans have access to MS care.
- 2. MAJOR CHANGES.** This is a new VHA Handbook.
- 3. RELATED DIRECTIVE.** None.
- 4. RESPONSIBLE OFFICE.** The Office of Patient Care Services (11), Medical-Surgical Services (111) is responsible for the contents of this Handbook. Questions may be referred to the National Director of Neurology at (202) 461-7120.
- 5. RECISSIONS.** None.
- 6. RECERTIFICATION.** This VHA Handbook is scheduled for recertification on or before the last working day of December 2014.

Gerald M. Cross, MD, FAAFP
Acting Under Secretary for Health

DISTRIBUTION: E-mailed to the VHA Publication Distribution List 12/10/09

MULTIPLE SCLEROSIS SYSTEM OF CARE PROCEDURES

CONTENTS

PARAGRAPH	PAGE
1. Purpose.....	1
2. Background and Authority.....	1
3. Scope.....	1
4. Responsible Offices	2
5. Definitions.....	2
6. National System of Multiple Sclerosis (MS) Care	4
7. MS System of Care Continuum	4
8. Population Served	9
9. Relationship to Department of Veterans Affairs (VA) Spinal Cord Injury and Disorders Centers (SCI/D)	9
10. Health Management Issues Through the Continuum of Care.....	10
11. MS Regional Programs	21
12. MS Support Programs.....	24
13. Multiple Sclerosis Centers of Excellence (MSCoE) Hub and Spoke Network.....	25
14. MS Education.....	26
15. Referral Guidelines	27
16. References.....	28

APPENDICES

A. Multiple Sclerosis Centers of Excellence (MSCoE) Regional Centers Staffing Calculations and Justification	A-1
B. Computerized Patient Records System (CPRS) MSCoE Progress Note Template	B-1

CONTENTS (continued)

PARAGRAPH	PAGE
C. MScOE Clinical Data Surveillance (CDS) Tool.....	C-1
D. Abbreviations.....	D-1
E. Web-Based Resources.....	E-1

MULTIPLE SCLEROSIS SYSTEM OF CARE PROCEDURES

1. PURPOSE

This Veterans Health Administration (VHA) Handbook establishes policy and procedures for health care services for Veterans with multiple sclerosis (MS). This Handbook describes the essential components and procedures of the MS program that are to be implemented nationally to ensure that all enrolled Veterans, wherever they live, have access to MS care.

2. BACKGROUND AND AUTHORITY

In 2001, Congress urged the VHA to establish two Multiple Sclerosis Centers of Excellence (MSCoE) for clinical care, education, and research, Conference report (H. Rept. 106-988), Senate Appropriations Committee Report (S. Rept. 106-410) and House Appropriations Committee report (H. Rept. 106-674) that accompanied Department of Veterans Affairs (VA)'s Fiscal Year 2001 Appropriation. In response, VA convened a committee of MS experts who defined the requirements for the two centers. The committee also mandated the establishment of national standards for the care of Veterans with MS and, as only two centers were to be funded, the development of a network of affiliated regional programs supporting local facilities and providers. In 2002, based on competitive applications, two centers were selected, one located at the VA Medical Center in Baltimore, Maryland, in Veteran Integrated Service Network (VISN) 5, serving VISNs 1-11. The other jointly based centers are located in the Seattle and the Portland VA Medical Centers in VISN 20, serving VISNs 12-23. The MSCoEs were made permanent by "The Veteran's Benefits, Healthcare and Information Technology Act of 2006."

3. SCOPE

The mission of the MSCoE is to support and maintain the health, independence, quality of life, and productivity of Veterans with MS through clinical care, education, and research.

a. MS is a unique disease due to its dynamic and progressive nature and requires special expertise to diagnose and manage. As part of the mission to provide access to high quality, comprehensive MS care for all Veterans within VHA, the MSCoE provides the leadership to implement this care plan. This Handbook outlines a continuum of services coordinated through designated multidisciplinary clinics called MS Regional Programs. By building the requirements for services on specifications of what must be available to each Veteran; it is designed to meet individual needs.

b. This Handbook defines requirements for services that must be provided at VA medical facilities. It is not the purpose of this Handbook to describe all aspects of MS treatment and programming that could be appropriate and effective. Sites are strongly recommended to go beyond these specifications in developing their MS programs in accordance with their resources and opportunities. VISNs and facilities are encouraged to engage in clinical and educational innovation as well as research to develop new strategies of care. These approaches permit the incorporation of best practices throughout VHA. *NOTE: Other services are at times mentioned,*

with wording indicating such services “may” be delivered or facilities are “recommended” to provide them. These indicate suggestions, not requirements.

c. The MSCoE structure and core functions include expert care initiatives and guidelines, education for providers and patients, and other clinical programs directed at enhancing the quality of MS care. A hub and spoke model (refer to: <http://www.va.gov/ms>) has been established for referrals within each VISN supplemented by a telemedicine network to facilitate nationwide coverage. MSCoE programs will maximize the use of VA’s Computerized Patient Record System (CPRS); VA national clinical databases; and telehealth resources to improve care coordination quality, access, and efficiency.

d. In contrast to other specialized VHA Centers where Veterans are referred to a designated regional center, the MSCoEs were charged with improving the care provided to MS patients without changing the setting of care. The MSCoEs also monitor VA’s MS population and its care needs.

4. RESPONSIBLE OFFICES

a. **Chief Consultant, Medical-Surgical Services.** The Chief Consultant, Medical-Surgical Services, is responsible for overseeing the integrated national system of MS care standards within the VHA.

b. **National Director of Neurology Services.** The National Director of Neurology Services is responsible for directing and overseeing access to high-quality, comprehensive MS care for all Veterans within VHA. The National Director of Neurology Services recognizes that local and regional issues may affect the implementation of the requirements in this Handbook. The National Director of Neurology Services will be kept informed of any difficulties as they arise or evolve.

c. **Multiple Sclerosis Centers of Excellence (MSCoE) Directors.** The MSCoE Directors are responsible for establishing MS standards of care, the development of MS Regional Programs, coordination of MS care, and providing expertise and education for providers and patients.

d. **VISN Directors and Facility Directors.** The VISN Directors and facility Directors are responsible for working in collaboration with the MSCoEs and the National Director, Neurology Services, to ensure coordination of all components of health care for Veterans with MS. MS care must be delivered by qualified, competent staff. All professional staff must have the clinical and administrative support they require in order to allow them to efficiently deliver the high-quality, multidisciplinary care outlined in this Handbook.

5. DEFINITIONS

a. **Multiple Sclerosis (MS).** MS is an immune-mediated demyelinating and axonal degenerative disease of the central nervous system (the brain, spinal cord, and optic nerves). MS is the most common progressive neurologic disorder of young adults, affecting 350,000 to

400,000 people in the United States. The median age of onset is 30 years. The disease is more common in women. By 15 years from first symptom onset, 20 percent require a cane to walk. This percentage increases to 69 percent by 40 years after onset. The number of Veterans with MS using VHA can be found in the annual report available on the MSCoE Web site (refer to: <http://www.va.gov/ms>).

b. **Epidemiology.** Epidemiology is the study of disease patterns and risk factors within populations. In relation to MS, epidemiology takes into consideration variations in demographics, geography, genetics, and environmental triggers. Epidemiologists contribute to the knowledge of MS by studying the relationships between these factors in an effort to understand who develops MS and why, and identify and explain areas with low or high rates of MS.

c. **Etiology.** Although the etiology of MS is unclear, current research indicates that MS is initiated by an environmental trigger in a genetically susceptible individual. While there has been exciting work showing several genes increase susceptibility for MS, genetics can at best explain only 30 percent of the susceptibility equation, as concordance rates for MS in identical twins range between 15 to 30 percent. Laboratory and clinical studies show there is an autoimmune attack on the central nervous system that results in myelin and neuronal cell damage with the ultimate loss of nerve function and varying degrees of disability.

d. **Diagnosis.** The diagnosis of MS is based on the history and neurological examination. To make a definitive diagnosis of MS, one must demonstrate neurological episodes separated in space and time. This is most efficiently achieved by applying the 2005 Revised McDonald MS Diagnostic Criteria (refer to: <http://www.mult-sclerosis.org/DiagnosticCriteria.html>). Supporting paraclinical evidence may include cerebrospinal fluid oligoclonal bands, visual-evoked potential studies, magnetic resonance imaging (MRI), and laboratory data to rule out diseases that mimic MS or are autoimmune in nature. Major conditions on the differential diagnosis include age-related white matter changes, central nervous system bacterial or viral infections, cervical spondylosis or stenosis, neoplasms, migraine, sarcoidosis, stroke, collagen vascular disease, vasculitis, and vitamin B12 deficiency. Laboratory studies need to be tailored to the patient and may include: complete blood count; chemistry panel; liver enzymes; thyroid-stimulating hormone (TSH), prothrombin time (PT) and partial thromboplastin time (PTT); serum B12 level; sedimentation rate; C-reactive protein; rheumatoid factor; anti-nuclear antibodies; Sjogren's antibodies; antiphospholipid antibodies; serum Venereal Disease Research Laboratory (VDRL) test; angiotensin converting enzyme; Human T-lymphocyte Virus I and II (HTLV I/II); Human Immunodeficiency Virus (HIV); and Lyme disease serology.

e. **Symptoms.** Common MS symptoms include fatigue, cognitive impairment, mood disorders, visual difficulties, motor and sensory deficits, incoordination, gait dysfunction, speech and swallowing deficits and impairments of bowel and bladder control as well as sexual functioning. Because the symptoms of MS are diverse, and occur dynamically over the course of many decades, patients are optimally managed in a comprehensive and specialized center.

f. **Clinical Course.** MS typically presents with intermittent neurological relapses and remissions. A relapse or exacerbation is a sudden new neurological symptom that lasts at least 24 hours. Most patients with MS develop permanent neurological deficits and enter a

progressive phase of the disease after the initial relapsing phase. There are four major subtypes of MS:

(1) **Relapsing-remitting MS (RR MS).** This is the most common subtype of MS (85 percent at onset) and is characterized by clearly defined relapses. Relapses are followed by periods of partial or complete recovery (remissions) that are free of disease-related progression.

(2) **Secondary Progressive MS (SP MS).** Patients with this subtype start with RR MS and then begin progressing with or without occasional relapses.

(3) **Progressive Relapsing MS (PR MS).** Patients with this subtype have a slow progression of disability from onset with periods of stability and occasional relapses (about 5 percent of patients from onset).

(4) **Primary Progressive MS (PP MS).** Patients with this subtype have progressive worsening in disability from onset without exacerbations. There may be changes in the rate of progression or periods of stability during the course of disease (about 10 percent of patients from onset).

g. **Disease Modifying Therapies (DMTs).** Several DMTs are available to treat MS that can reduce relapses and may slow disability progression. For optimal benefit, DMTs are best started early in the course of the disease. For additional discussion of DMTs, see section 10.d.

h. **Hub and Spoke Care Model.** The MS system of care consists of an integrated network of care based on a hub and spoke model. Within this model, comprehensive, multidisciplinary specialty MS care is centrally located at designated MS Regional Programs. MS Regional Programs are chosen and approved by the Director of the MSCoE based on specified criteria (see section 11 – MS Regional Programs). Spokes are primarily outpatient facilities within the local area of the identified MS Regional Program (hub) or VA medical center.

6. NATIONAL SYSTEM OF MS CARE

The MS system of care consists of at least one MS Regional Program (hub) in each VISN. Veterans with MS within each VISN are identified through MSCoE databases. The Director of each MS Regional Program needs to be informed of the location of such Veterans within their catchment area to establish communications with local providers. Veterans with MS may be referred to MS Regional Programs as needed for specialty care evaluations. Primary care and, in some cases, specialty care is provided at locally accessible VA facilities within specified referral areas (refer to: <http://www.va.gov/ms>).

7. MS SYSTEM OF CARE CONTINUUM

a. **Location of Care.** The location of care is dictated by the needs of the Veterans with MS. Care will take place as close to home as possible and may be delivered in a variety of settings and methods, to include telehealth. Regardless of the location, if MS is the primary or a

secondary diagnosis, it is recommended that providers of MS care be made aware of the Veteran's admission into the VA system. Overall, MS care needs to be comprehensive and multidisciplinary.

b. **Clinical Services.** The MS system of care ensures timely access to the VHA and subspecialty services. The multidisciplinary care for Veterans with MS must be coordinated through MS care teams, with appointments made in a timely manner to meet VA standards for all MS-related and general clinical problems. Through the MS system of care, age-appropriate screening and prevention programs (e.g., immunizations and breast and cervical cancer screening) must be initiated to meet current VHA guidelines for patients with MS. The following discussion outlines the broad clinical services offered to Veterans with MS within VHA.

(1) **Emergency Care.** Veterans with MS requiring immediate medical attention will present to emergency services. For MS-related issues, it is recommended that the Veteran be evaluated by a provider knowledgeable about MS and that the MS network be informed. The MS specialist needs to be consulted for MS-related issues when clinically appropriate, to optimize coordination of care. *NOTE: For all emergency care visits, it is recommended to alert the MS specialist as a co-signer on the CPRS progress note.*

(2) **Primary Care.** Veterans with MS will be assigned a primary care provider for preventive and general medical care at all VA medical centers. The primary health care provider assumes ongoing responsibility for prevention, health maintenance, and treatment for illness. Preventive strategies such as smoking cessation and immunizations are especially important in Veterans with MS. In facilities with extensive specialty care services, the MS care team needs to be available to advise and assist primary care providers to coordinate and/or assume care if the Veteran experiences an MS exacerbation or other MS-related problem. In facilities without specialty care services, the closest MS Regional Program must be available to advise or assume care should it be necessary and the use of telehealth can be used to facilitate this communication. Coordination between primary and MS specialty care after inpatient admissions is critical.

(3) **MS Specialty Care.** It is recommended that all Veterans with MS be referred to MS specialty care whenever possible. Referral to MS specialty care is recommended on at least an annual basis. More frequent follow-up may be necessary based upon individual disease management. Patients with unstable disease or complex symptom management issues may require more frequent specialty care, follow-up, or referral to other specialists. The use of VHA's national clinical videoconferencing networking for telehealth may be particularly beneficial for accessing MS specialty care. *NOTE: For all MS-related visits, it is recommended that the MS specialist alert the primary care provider by adding the provider as a co-signer to the CPRS progress note.*

(4) **Rehabilitation.** Rehabilitation services are commonly required in MS care. Multiple rehabilitation specialties (i.e., psychiatry, physical therapy, occupational therapy, recreation therapy, speech therapy, and kinesiotherapy) are often necessary to address the rehabilitation issues of Veterans with MS. Both inpatient and outpatient rehabilitation services, as well as

telehealth rehabilitation services, may be a part of the MS treatment plan. The goals of rehabilitation are to maximize functional outcomes, reduce activity restrictions, and lessen limitations on meaningful social role participation.

(5) **Palliative Care.** Palliative care is a holistic approach to managing advanced or distressing MS symptoms. The goal of such care is to relieve symptoms caused by MS rather than modify the disease course. End-of-life palliative care occurs when complications related to MS or complications typical of advanced age present a serious and incurable threat to life. Goals of palliative care revolve around relieving suffering and supporting the best possible quality of life for people with MS and their families.

(a) The following signal a need to relieve suffering and address the patient's well-being aided by palliative care specialists:

1. Physical deterioration evidenced by repeated hospitalization for urinary tract infections or aspiration pneumonia;
2. Dysphagia and weight loss, requiring discussion of feeding tubes;
3. Neurogenic bowel and bladder, requiring discussion of urostomy and colostomy tubes;
4. Dyspnea or symptoms of hypoventilation, requiring non-invasive or invasive ventilation; and
5. Intractable pain.

(b) Palliative care specialists in the VHA should link with providers, patients, and families in an ongoing dialogue to determine the goals of care, including advanced directives, resuscitation status, and the use of potentially life-prolonging care.

(c) Palliative care can be provided in all settings: home, outpatient clinic, long-term-care facility, hospital, or intensive care units.

(d) Palliative care demonstrates compassion, commitment, and hopefulness that suffering can be relieved.

(6) **Respite Care.** Respite care provides caregivers temporary relief from the responsibilities of caring for individuals with MS. Respite literally means a period of rest and is recognized as an important consideration for families and caregivers of physically dependent Veterans. Respite care need not be limited to a long term care unit, but rather in an age and diagnosis-appropriate setting with trained staff. Each Veteran requiring attendant care should be offered respite care at a facility approved by the referring VA medical center. The duration of any respite care admission, absent complicating medical factors for patient or caregiver, will not exceed 14 days. The total of all respite care for a Veteran in a year, absent complicating medical factors, is not to exceed 30 days. Any individual who has been hospitalized is not eligible for respite care until 1 month after discharge from an inpatient stay.

(7) **Home Care.** Medical, rehabilitation, and preventive services determined necessary to sustain the Veteran with MS in the community needs to be provided. This will require collaboration between Social Work Service (SWS), Care Coordination Home Telehealth (CCHT), primary care, and specialty care.

(8) **Long-term care**

(a) The VHA system of care is committed to supporting a full continuum of care for Veterans with MS including long-term care. The goal of long-term care is to assist Veterans with MS to attain or maintain a community level of adjustment and maximal independence despite the loss of functional ability due to the aging process, loss of a primary caregiver, medical complications or progression of their disease. Care Coordination Home Telehealth (CCHT) monitors patients at home using home telehealth technologies in order to prevent or delay Veterans needing to leave their home for the management of chronic conditions and to provide non-institutional care.

(b) The continuum of extended care services for Veterans with MS is a mix of services designed to meet eligibility requirements, individual need, family needs, personal preference (choice), and the promotion of independent community living whenever possible. Options within VHA include care at a designated VA long-term care facility, VA nursing home care unit, home care services, homemaker or home health aid services, adult day health care, contract home health care, home-based primary care, community residential care, sub-acute intermediate care, Geriatric Evaluation and Management Unit (GEMU), Geriatric Research and Education Clinical Center (GRECC), assisted living, state nursing homes, domiciliary care, respite care, and hospice care. *NOTE: The preceding list is not all-inclusive nor are all services available in all VA health care settings.*

(c) Any nursing home referral needs to include a summary of the interdisciplinary team's recommendations on the specific services and resources that the Veteran requires to maintain functional status, achieve maximal independence, reduce social role limitation, and enhance quality of life.

(d) It is expected that the Veteran with MS, who resides in a long-term care facility, continue to have access to the MSCoE network.

(9) **Mental Health Care.** Mental health issues are common in individuals with MS and are frequently overshadowed by their physical problems. All providers caring for persons with MS need to screen for mental health issues, offer treatment, and make appropriate referrals. Mood disorders need to be assessed regularly, including suicide risk assessment if significant depression is identified. All Veterans with MS must have access to mental health and neuropsychological services.

(10) **Social Work Services.** Veterans with MS must have access to comprehensive social work services throughout the course of their illness. Social workers participate in the planning, implementation, and evaluation of treatment programs for MS patients. Social workers participate in the initial assessment of the patient, placing special emphasis on the psychosocial

aspects of the problem(s) and formulate a social work component of the overall treatment plan. Social workers' functional responsibilities are directed toward:

- (a) Promoting mental, vocational, and social rehabilitation;
- (b) Facilitating the individual's return to the community at the highest level of functioning possible;
- (c) Advocating for health care services both within and outside of VHA (e.g., VA prosthetic items, Medicare, Medicaid, and Social Security Disability);
- (d) Providing case management to Veterans and their caregivers;
- (e) Providing linkages and referrals to access community supportive services for MS;
- (f) Assisting with alternative living arrangements when necessary;
- (g) Advising patients regarding Veteran's benefits and compensation programs (e.g., MS service-connection, VA Aid and Attendance funding, and VA Vocational Rehabilitation); and
- (h) Assisting with travel benefits.

(11) **Care Coordination Telehealth Services.** Care Coordination in VHA is defined as the use of health informatics, disease management, and telehealth technologies to extend and enhance care and case management. Telehealth supports VHA's strategic initiatives to improve access and enhance the quality of care provided to patients. Care Coordination services span the continuum of care and are categorized in VHA as:

(a) Care Coordination/Home Telehealth (CCHT). CCHT monitors patients at home using home telehealth technologies in order to prevent or delay Veterans needing to leave their home for the management of chronic conditions and to provide non-institutional care.

(b) Care Coordination/General Telehealth (CCGT). CCGT involves real-time videoconferencing technologies, with supportive peripheral devices, to provide care and consultation between clinics and hospitals, and hospitals and other hospitals.

(c) Care Coordination/Store-and Forward (CCSF) Telehealth. CCSF uses technologies to acquire and store clinical information (e.g. data, image, sound, video) that is then forwarded to (or retrieved by) another site for clinical evaluation.

(d) The Office of Care Coordination Services (CCS). CCS, within the Office of Patient Care Services, is the VHA program office organizationally responsible for telehealth/telemedicine (telehealth). CCS oversees development, implementation and ongoing refinement of the clinical, technology, and business processes that ensure robust and sustainable telehealth-based services are available to care for Veteran patients. This is accomplished through the provision of operations manuals for the development of telehealth programs and regular document reviews and in-person site visits to VISN telehealth programs utilizing a set of

Conditions of Participation (CoP) for Care Coordination Telehealth (CCT) programs. Telehealth supports VHA's strategic initiatives to improve access and enhance the quality of care provided to patients.

(e) MS CoE and CCS collaborate to develop telehealth programs within the VISNs for CCGT, CCHT, and CCSF that will address the specific needs of Veterans with MS. To ensure quality and safety standards are met, MS CoE's and CCS need to develop policies that are in line with national telehealth operations and goals to address issues that are unique to the MS population and system of care.

(f) Close collaboration at the VISN and local level is also necessary so that clinical, operational and technical processes are put in place that are in accordance with CCS Conditions of Participation (CoP) requirements and national telehealth standards. To accomplish this, MS hub and spoke network site staff collaborate with their respective VISN and local Telehealth Program Manager(s) to review and comply with requirements outlined in the CoPs such as:

1. Telehealth training and credentialing;
2. Documentation, coding and workload capture;
3. National telehealth performance measures and monitors; and
4. Equipment management and technology maintenance.

8. POPULATION SERVED

The MS hub and spoke network serves all Veterans with a diagnosis of MS, those with suspected MS, and those being evaluated for a diagnosis of MS. In addition, Veterans, family members, home caregivers, health care providers, and administrative staff who seek information about MS are included in the target population served by the MS CoE.

9. RELATIONSHIP TO VA SPINAL CORD INJURY AND DISORDERS (SCI/D) CENTERS

The MS CoE recognizes that the resources provided to the SCI/D System of Care are primarily for Veterans with stable symptoms due to injury to or disease of the spinal cord. MS is an unpredictable and progressive disease that frequently affects the spinal cord and requires different treatment approaches and expertise depending upon the stage of disease. Treatment services and programs for the MS population are the primary responsibility of the National Director of Neurology. However, the delivery of MS services is appropriately shared by Neurology Service, Rehabilitation Medicine Service, SCI/D Service, and Primary Care Medicine, according to the patient's identified needs and the professional expertise available in each of these four programs. To the extent resources allow, care within an SCI/D Center for individuals with MS who have spinal cord disease may, in some cases, be appropriate.

10. HEALTH MANAGEMENT ISSUES THROUGH THE CONTINUUM OF CARE

MS has both acute and chronic features; therefore care must be tailored to an individual patient's needs. The goal of MS management is to slow disease progression, prevent complications, and maximize quality of life.

a. **Early Diagnosis of MS.** The diagnosis of MS needs to be entertained as soon as possible after an initial neurological attack or progressive syndrome compatible with demyelinating disease. The work-up needs to follow the revised McDonald Diagnostic criteria (refer to: <http://www.multiple-sclerosis.org/DiagnosticCriteria.html>). Confirmation of MS by these same criteria needs to be made in Veterans initially presenting to the VHA who carry an MS diagnosis.

b. **Clinical Evaluations and Documentation.** (1) MS-related clinical evaluations must be documented in CPRS. A standardized CPRS MSCoE Progress Note Template (Appendix B) has been developed to assist with documentation. This template can be obtained from the MSCoEs and installed with the assistance of the local VA Medical Center Information Resource Management Service.

(1) The MSCoE Clinical Data Surveillance Tool (MSCoE CDS Tool) (Appendix C) is a Web-based tool that includes core clinical variables on MS. Each MS Regional Center is responsible for capturing these data on their referral MS population each year. These variables assist in the surveillance activities of the MSCoE and are stored on the MSCoE registry. National statistics on the VA MS population and assessments for each MS Regional Program will be calculated by the MSCoE-East and MSCoE-West annually. Core MS variables on the MSCoE CDS Tool include the following:

- (a) Demographics;
- (b) MS diagnosis and initial presentation;
- (c) MS disease course;
- (d) MS disability (Kurtzke DSS); and
- (e) MS disease modifying medication history.

NOTE: The expectation is that the MS CDS Tool will be completed at each annual exam, as described below.

c. **Annual Exam.** Every Veteran with a diagnosis of MS needs to have an annual general and neurological examination.

(1) This evaluation includes elements of preventive health care defined for the general Veteran population, provided there are no contraindications for doing so.

(2) The evaluation may need to be accomplished in one inpatient visit, one outpatient visit, several outpatient visits, or via telehealth.

(3) The MS Regional Programs are responsible for ensuring the MS patients in their region are evaluated annually either at MS support programs (spoke facilities) or at the Regional Center site.

(4) If not offered in primary care, Veterans with MS need to be encouraged to have a yearly influenza vaccination and a pneumococcal vaccination per the Center for Disease Control and Prevention (CDC) recommendations (refer to: <http://www.cdc.gov/mmwr/PDF/wk/mm5753-Immunization.pdf>). **NOTE:** *At the present time, the CDC recommends one-time re-vaccination after 5 years for persons with chronic renal failure or nephrotic syndrome; functional or anatomic asplenia (e.g., sickle cell disease or splenectomy); and for persons with immunocompromising conditions. For persons aged 65 years and older, the CDC recommends one-time re-vaccination if they were vaccinated 5 or more years previously and were aged less than 65 years at the time of primary vaccination.*

(5) The recommended annual neurological evaluation needs to include:

(a) A comprehensive history and neurological exam documenting core outcomes in the MSCoE CDS Tool (Appendix C).

(b) Laboratory evaluation as clinically appropriate.

(c) Assessment of vision, cognition, mood disorders, fatigue, spasticity, pain, and bladder, bowel, and sexual functioning. A number of individual scales allow for an objective assessment of these common MS symptoms.

1. Kurtzke Expanded Disability Status Scale (<http://www.multiple-sclerosis.org/expandeddisabilitystatusscale.html>),

2. MS Functional Composite (http://em.sen.es/adjuntos/11_04_31_398.pdf),

3. Fatigue Severity Scale (<http://www.multiple-sclerosis.org/fatigueseverityscale.html>),

4. Modified Ashworth Scale (<http://www.odstockmedical.com/pdfs/ashworth.pdf>),

5. Beck Depression Inventory (see para.16).

(d) Assessment of mobility, self-care, vocational, and social support needs.

(e) MRI of the brain and cervical and thoracic spine as clinically appropriate. **NOTE:** *To standardize MRI analysis within and between VA medical facilities, the Consortium of Multiple Sclerosis Centers (CMSC) MRI protocol is recommended (refer to: <http://www.msca.org/cmssc/images/pdf/MRIprotocol2003.pdf> and <http://www.ajnr.org/cgi/content/full/27/2/455>). Renal function should be assessed prior to giving gadolinium contrast with MRI to evaluate risk for nephrogenic systemic fibrosis (NSF). NSF following gadolinium contrast has rarely been reported in individuals with impaired renal function.*

(f) Multidisciplinary referrals, which may include physical therapy, occupational therapy, kinesiotherapy, recreation therapy, vocational rehabilitation, speech therapy, psychology, neuropsychology, mental health, social work, prosthetics, pulmonary medicine, sleep medicine, pain management, palliative care, community health nursing and home health care.

d. MS Disease Modifying Therapy (DMT)

(1) Veterans with MS who are appropriate candidates for DMTs must have access to these agents as early in the disease course as possible. During the span of a clinical trial, many DMTs have been shown to reduce relapses as well as neurologic disability. Use of DMTs is not limited by the frequency of relapse, age, or level of disability. Treatment continues indefinitely unless there is clear deterioration, intolerable side effects, or better treatment becomes available. Under the current VHA policy, all FDA approved DMTs for MS are included in the National VA formulary. **NOTE:** Refer to VA Pharmacy Benefits Management (PBM) Intranet site for guidance on medications used for the treatment of patients with MS (<http://vawww.pbm.va.gov>). This is an internal VA Web site, not available to the public.

(2) The FDA-approved disease modifying medications specifically for MS are noted by an asterisk. Other medications listed have been tested in MS clinical trials of safety and efficacy. Evidence for the use of these disease modifying agents has been recently reviewed (Goodin et al, 2002).

(3) Immunomodulating agents

- (a) Interferon beta (Avonex®, Betaseron®, Rebif®)*
- (b) Glatiramer acetate (Copaxone®)*
- (c) Natalizumab (Tysabri®)*

(4) Immunosuppressive agents

- (a) Cyclophosphamide (Cytosan®)
- (b) Azathioprine (Imuran®)
- (c) Methotrexate (Rheumatrex®)
- (d) 2-chlorodeoxyadenosine (Cladribine®)
- (e) Immunoglobulin (IVIG®)
- (f) Methylprednisolone (Solumedrol®)
- (g) Mycophenolate mofetil (CellCept®)

(h) Mitoxantrone (Novantrone®)*

e. **Management of Relapses.** A relapse is the acute appearance of at least one neurological symptom that is present for more than 24 hours in the absence of fever or infection.

(1) The standard treatment for relapses associated with significant disability is 500-1,000 mg of intravenous methylprednisolone (IVMP) over 3 to 5 days. This may be followed by a short course of oral prednisone for a total combined IV and oral course of 2 to 3 weeks. Intravenous dexamethasone (Decadron®) may be used in place of IVMP at 160-180 mg/day for 3 to 5 days. *NOTE: Clinical trial evidence indicates a short course of IVMP is the treatment of choice for acute exacerbations to diminish acute neurological dysfunction.* Intravenous steroids may be administered in several settings, including a VA medical center, Community Based Outpatient Clinics (CBOC), non-VA infusion center, or the patient's home. For severe MS relapses, plasma exchange may be considered.

(2) The effect of IVMP on the long-term course of disease is not established, and mild relapses do not necessarily require treatment. An oral taper of steroids has unclear benefit.

f. **MS Symptomatic Therapy**

(1) **Fatigue.** Assessment of fatigue needs to include a review of medicines and comorbid conditions that can produce fatigue. Primary or secondary sleep impairments, anemia, thyroid disease, and mental health conditions may be responsible for fatigue. Appropriate evaluations need to include a complete blood count, thyroid stimulating hormone, and referral to a sleep disorders clinic.

(a) Non-pharmacological management of fatigue includes:

1. Education regarding sleep hygiene (e.g., relaxing pre-sleep routine, avoid caffeine in evening);

2. Energy efficiency techniques;

3. Schedule reorganization: perform demanding tasks early in day, maintain regular exercise and balanced nutrition; and

4. Temperature regulation: maintain a cool environment or cooling therapy (e.g., cooling vests).

(b) Pharmacological management of fatigue includes:

1. Treatment of underlying conditions such as spasticity or depression;

2. Central nervous system stimulants (e.g., methylphenidate-Ritalin®); and

3. Amantadine hydrochloride.

(2) **Spasticity.** Assessment of spasticity must use an objective scale such as the Modified Ashworth score (refer to: <http://www.odstockmedical.com/pdfs/ashworth.pdf>). In addition, precipitating factors that may induce spasticity and the secondary impairments and disabilities associated with spasticity need to be assessed (e.g., interruption in sleep, pain, decreased mobility, falls, pressure sores, and contractures).

(a) Non-pharmacologic management of spasticity includes:

1. Stretching;
2. Positioning;
3. Orthotics;
4. Range of motion;
5. Thermomodality;
6. Relaxation techniques; and

7. Daily exercise programs. (*NOTE: The aforementioned should incorporate the expertise of a rehabilitation medicine specialist.*)

(b) Pharmacologic management of spasticity includes:

1. Central acting agents (e.g. baclofen and tizanidine)-(Zanaflex®);
2. Benzodiazepines (e.g. diazepam)-(Valium®);
3. Anticonvulsants (e.g. gabapentin)-(Neurontin®); and
4. Botulism toxin (Botox®)

(c) Surgical management of spasticity includes;

1. Intrathecal pump for baclofen;
2. Spinal nerve blocks; and
3. Ablative procedures (e.g., dorsal rhizotomy and tenotomy).

(3) **Bowel And Bladder Management.** Bowel and bladder dysfunction can present early in MS and lead not only to impaired quality of life but also to medical complications if not assessed and treated. Veterans with MS need to be assessed regularly for bowel and bladder dysfunction with appropriate assessments and education. This may be done in the MS specialty clinic or in the primary care setting. Diagnostic evaluation needs to be available when needed, including ultrasound, urodynamics, cystoscopy, and endoscopy.

(a) Neurogenic Bowel. Constipation may be defined as two or fewer bowel movements each week. Constipation commonly occurs in patients with MS. Fecal incontinence rarely occurs. Abnormal bowel motility and sensation related to MS, inadequate fluid intake, and untoward effects of medications are common culprits that lead to bowel dysfunction. Assessment of bowel function may include review of the frequency of bowel movements, history of constipation, bowel urgency, incontinence, and imaging reports (e.g., abdominal x-ray). A bowel care program for MS patients with bowel dysfunction can include the following:

1. Bowel training;
2. Increase fluids;
3. Increase fiber;
4. Bulk forming agents [e.g., psyllium (Metamucil®)];
5. Stool softeners (e.g., docusate-Sodium) (Colace®);
6. Stimulant laxatives (e.g., senna and bisacodyl)-(Dulcolax®);
7. Osmotic laxatives (e.g., polyethylene glycol and magnesium citrate);
8. Lubricants (e.g., mineral oil); and
9. Gastroenterology and surgical consultation

(b) Neurogenic Bladder. Assessment of bladder function needs to include the following: history of bladder urgency, frequency, hesitancy, incontinence, and nocturnal voiding; post void residual (PVR) volume via bladder ultrasound or catheterization; urinary tract infection history, urinalysis, and urine culture. Disorders of the bladder in MS and the management of those disorders may include:

1. Bladder failure to store;
 - a. Bladder training,
 - b. Decrease in bladder irritants (caffeine, aspartame, alcohol),
 - c. Protective garments/external urinary drainage devices,
 - d. Anticholinergic/antimuscarinic agents (e.g., oxybutynin)-(Ditropan®),
 - e. Avoidance of diuretics, and
 - f. Antispasticity medication (e.g., baclofen).
2. Bladder failure to empty:

- a. Antispasticity medication,
- b. Alpha blockers (e.g., terazosin-(Hytrin®) and doxazosin-(Cardura®),
- c. Intermittent catheterization and indwelling Foley catheter,
- d. Suprapubic catheter, and
- e. Ileal conduit.

(4) **Sexual Dysfunction.** Up to 70 percent of women and 90 percent of men with MS report they have problems with sexual function. Difficulties include loss of libido, reduced genital sensation, failure to achieve orgasm, and erectile dysfunction. Sexual dysfunction in MS may be due to damage to the responsible spinal or brain pathways, mood disorders, fatigue, pain, or spasticity. There are a variety of treatments that may be appropriate for sexual dysfunction, including medications for erectile dysfunction (e.g., vardenafil (Viagra®)), lubrication, treatment of fatigue or spasticity, and counseling.

(5) **Fertility Issues.** MS does not affect one's basic fertility. However, sexual and other physical dysfunction may make it challenging to conceive. Overall sexual health and the desire for having children needs to be addressed periodically by MS care providers. Precautions for acquiring sexually transmitted diseases and birth control need to be discussed.

(6) **Cognitive Dysfunction and Mental Health.** Mental health issues are common in individuals with MS. Their recognition is frequently overshadowed by their physical problems. Up to 70 percent of MS patients have some degree of cognitive dysfunction during the course of their disease, but clinical dementia is rare. Approximately 50 percent of persons with MS experience depression and 10-15 percent experience emotional variability. Psychological challenges arise from the unpredictable nature of relapses, the uncertainty of disease progression, difficulties with coping with relationships, and professional stress.

(a) Veterans with MS need to be screened for cognitive dysfunction as part of an annual neurological examination. The differential diagnosis for cognitive dysfunction in patients with MS may include the untoward effects of medications, Alzheimer's dementia, multi infarct dementia, hypothyroidism, B12 deficiency, and depression. **NOTE:** *For a thorough assessment, standardized cognitive batteries, such as the Minimal Assessment of Cognitive Function in MS that focus on MS-related cognitive dysfunction can be administered by trained health care staff.* A more detailed examination by a neuropsychologist may be needed to address specific cognitive problems or provide documentation of occupational capacity, driving abilities, and safety in activities of daily living. Such an examination is often of benefit for disability claims and rehabilitation planning.

(b) Veterans with MS need to be regularly assessed for changes in mood and anxiety. Assessment instruments may include the Beck Depression Inventory (BDI) (refer to REFERENCE section #16), Multiple Sclerosis Quality of Life Instrument (<http://www.nationalmssociety.org/for-professionals/researchers/clinical-study->

measures/msqli/index.aspx); Center for Epidemiological Studies-Depression Scale (CES-D) or VA CPRS Clinical Reminder Screens for Depression, Post Traumatic Stress Disorder (PTSD), and Suicide. Referral to psychiatry, psychology or neuropsychology may be required for assistance in the management of mental health disorders.

(c) The MS health care team in coordination with mental health providers needs to be responsible for:

1. Screening for mental health issues and making treatment recommendations;
2. Screening for cognitive dysfunction and making recommendations for cognitive compensation strategies;
3. Maximizing mental, social, and interpersonal functioning of Veterans with MS;
4. Providing education to Veterans, family members, caregivers, and multidisciplinary team members on the psychosocial impact of illness and disease progression; and
5. Providing counseling sessions for individual patients and families.

(d) Non-pharmacologic management for cognitive dysfunction and mental health disorders may be effective in improving symptoms. Common cognitive and mental health problems with potential interventions are:

1. Episodic memory deficits: look for visual and verbal cues, use voice recorder, voice mail, notes, electronic organizers;
2. Attention/information processing dysfunction: limit multitasking, decrease stimuli, slow the conversation, make schedules, repetition;
3. Verbal fluency problems: pace conversation, involve others;
4. Executive dysfunction: simplify tasks, use schedule and visual organizers;
5. Visual perceptual defects: slow pace, use large clear font when reading;
6. Language dysfunction: plan discussion, use written notes and tape recorder;
7. Decreased attention span: focusing techniques, simplify tasks, involve others;
8. Family training to assist and adapt to cognitive and mental health problems; and
9. Physical exercise and recreation therapy for improvement in mood, memory, and attention.

(e) Pharmacological management of cognitive and mental health disorders may be required. Potential therapies may include:

1. Central nervous system (CNS) stimulants;
2. Acetylcholinesterase inhibitors;
3. Antidepressants;
4. Antipsychotics;
5. Anxiolytic agents; and
6. Other mood stabilizers (e.g., valproate).

(7) **Pain.** Up to 50 percent of people with MS suffer from chronic pain. Veterans with MS who present with pain need proper assessment and management. Not all pain is attributable to MS, and as with other signs and symptoms, other causes, from radiculopathies to arthritis among them, need be considered. Pain in MS takes on many forms and has many causes. Some of these include neurological pain from central nervous system dysfunction, muscle pain from cramps and spasms, musculoskeletal pain from maladaptive joint positions due to weakness, and pain due to over-exertion and exhaustion in an effort to cope with weakness. Pain may be secondary to neuromuscular or musculoskeletal impairments such as carpal tunnel syndrome, osteoarthritis, or radiculopathies. Depression and anxiety often enhance pain perception.

(a) Non-pharmacologic management of pain includes:

1. Physical therapy and related modalities such as exercise, heat, ice, Transcutaneous Electrical Nerve Stimulation (TENS) units, and aquatic therapy;
2. Positioning assistance and adaptive equipment (splints, electrical stimulation devices, alternating pressure mattresses, hospital beds, wheel chair seating modifications);
3. Behavioral techniques (relaxation, cognitive therapy, support groups); and
4. Education.

(b) Pharmacologic management of pain includes:

1. Topical balms and anesthetic agents;
2. Anticonvulsants;
3. Antidepressants;
4. Antiarrhythmics;
5. Non-narcotic and narcotic opioids; and
6. Nonsteroidal anti-inflammatory medications.

(c) Invasive treatments for pain include:

1. Nerve and facet blocks; and
2. Neurostimulators.

(8) **Visual Disturbances.** Acute visual loss needs to be assessed by examining cranial nerves II, III, IV, and VI and determining the patient's visual acuity; visual fields; color desaturation; disc funduscopy; pupil size and reaction to light; and extraocular movements. Potential diagnostic tools include contrast sensitivity, visual evoked potentials, ophthalmology referral for formal visual fields, and optical coherence tomography of the retinal nerve fiber layer. Common visual disturbances in MS and potential treatments for them are:

(a) Painful Vision Loss (optic neuritis) or Diplopia;

1. High dose IV corticosteroids;
2. Symptomatic patching; and
3. Refer to ophthalmology.

(b) Nystagmus;

1. Benzodiazepines;
2. Antispasticity agents (e.g., baclofen);
3. Anticonvulsants; and
4. Methyl-D-aspartate receptor antagonists.

g. **MS Rehabilitation**

(1) **Overview.** Rehabilitation is a necessary feature in the continuum of MS care. Rehabilitation services are designed to improve health and welfare and assist in achieving one's maximum physical, social, psychological, and vocational potential. The need for rehabilitation services needs to be assessed regularly with appropriate referrals made. Due to the dynamic nature of MS, requirements for rehabilitation services will vary. Evaluation for referrals is especially important after acute MS exacerbations or hospitalizations for other comorbid conditions (e.g., pneumonia). Rehabilitation consults may include:

- (a) Physical therapy;
- (b) Occupational therapy;
- (c) Kinesiotherapy;

- (d) Aquatic Therapy (**NOTE:** 4 below for heat sensitivity);
- (e) Rehabilitation nursing;
- (f) Speech therapy;
- (g) Driver's training/retraining;
- (h) Prosthetic services;
- (i) Vocational rehabilitation;
- (j) Recreation therapy;
- (k) Transportation assessment;
- (l) Home care and long term care assessment;
- (m) Home safety evaluation;
- (n) Fall assessment;
- (o) Assistive technologies assessment; and
- (p) Wheelchair seating and pressure mapping.

(2) **Speech and Swallowing Dysfunction.** Speech dysfunction in MS may be due to difficulties with articulation or related to underlying cognitive problems. Dysphagia or difficulties swallowing typically occurs with advanced MS but can present at any time. There may be coughing or choking when eating solids or liquids or both, with possible aspiration into the trachea. Speech and swallowing dysfunction need to be periodically assessed in patients with MS. When problems are noted, a referral to a speech and language pathologist should be made for further work-up and management of such problems. Use of speech assistive devices, modification of the diet, or a feeding tube may be appropriate interventions.

(3) **Respiratory Muscle Function.** Motor deficits in MS can involve the respiratory muscles. Both strength and endurance can be affected with decrements in maximal inspiratory pressure (MIP) and maximal expiratory pressure (MEP). Non-ambulatory patients with MS with Expanded Disability Status Scale levels greater than 6.5 have MIPs of 27-74 percent of predicted values. Acute respiratory (ventilatory) failure can occur in MS and must be promptly diagnosed and appropriately treated. Patients, especially if non-ambulatory, may be unaware of this condition. Simple measures, such as ability to blow out a match or candle, counting from 1-20 without pause, and timed breath-holding are of value in alerting the clinician to potential problems in this area. Assessment of respiratory muscle strength by MIP and MEP and respirator muscle endurance (by maximal voluntary ventilation) needs to be performed every 1 to 3 years depending on the severity of pulmonary impairment. These tests can be performed with the assistance of the pulmonary function lab or via portable hand-held devices. Referral to

pulmonary services for evaluation and discussion of treatment options is appropriate for patients with significant respiratory weakness or dysfunction. Rehabilitation of respiratory muscle weakness includes the following options:

- (a) Threshold EMT (expiratory) trainer for expiratory muscle weakness; and
- (b) Threshold IMT (inspiratory) trainer for inspiratory muscle weakness.

(4) **Heat Sensitivity.** MS symptoms often temporarily worsen in hot weather, with fevers, or when taking a hot bath or shower. Treatment strategies to lessen the effects of heat include:

- (a) Remain in air conditioned environments;
- (b) Use cooling vests or caps before, during, or after exercising or when outdoors in hot weather;
- (c) Wear loose-fitting, lightweight clothing; and
- (d) Exercise in a cool pool.

h. **Complementary and Alternative Medicine (CAM).** About 75 percent of people with MS in the US use CAM, generally in combination with prescribed therapies. CAM therapies are broad and range from dietary supplements and biofeedback to acupuncture. They are generally considered outside the realm of conventional medicine. Many therapies in this category may be helpful in the symptomatic management of MS, but for the most part, they are not regulated as to content or safety. They may not be available within the VA pharmacy service or contracts. For specific recommendations on these therapies for MS see the National Center for Complementary and Alternative Medicine's Web site (refer to: <http://nccam.nih.gov>) and Complimentary and Alternative Medicine and MS (Bowling, 2007).

11. MS REGIONAL PROGRAMS

In addition to the MSCoE-East and MSCoE-West facilities, designated MS Regional Programs (see <http://www.va.gov/ms> for list) provide MS specialty care with a continuum of acute, chronic, and long-term care services consistent with VHA policies. There is at least one MS Regional Program in each VISN. To support the specialty care of Veterans with MS, the Veterans Equitable Resource Allocation (VERA) system increased the annual payment for MS in 2007 (refer to: http://vaww.arc.med.va.gov/references/faqs/faqs/faq_ll.html. *This is an internal Web site, not available to the public.*) Veterans with a diagnosis of MS and not receiving DMTs were elevated to VERA Price Group 4. In addition, Veterans with MS receiving a DMT were elevated to VERA Price Group 5. It should be noted that Veterans with spinal cord involvement must be coded as such, which makes them eligible for complex supportive care, VERA Price Group 8.

a. **Approval of MS Regional Programs.** MS Regional Programs are approved by the Chief Consultant for Neurology Services and the MSCoE-West or MSCoE-East directors. They are organized under a clinical service within a VA medical facility, and in most cases, the

supervising service will be neurology or rehabilitation medicine. Each MS Regional Program serves a high density region of Veterans with MS within a VISN defined as greater than 100 patients with MS. The establishment of a new MS Regional Program must follow VA physical plant, staffing, and resource requirements and must be located at VA medical facilities that are capable of providing MS tertiary care at the facility or through referral.

b. **Scope of Services of MS Regional Programs.** The scope of MS Regional Program services addresses the unique aspects of delivering specialty health care services to individuals with MS. Due to the dynamic aspects of the disease, MS Regional Programs must be located at VA medical facilities that are capable of providing the full spectrum of tertiary care. The MS Regional Program must include FDA-approved MS therapies and be capable of providing services defined in paragraph 10 of this Handbook. The delivery of specialized services may require linkage with other programs within a VISN or region. Overall care related to MS needs to be directed and integrated by the MS Regional Program.

c. **MS Regional Program Team Personnel**

(1) **Chief, MS Regional Program.** The position of MS Regional Program Chief must be filled by a physician who may serve the given VA medical facility through a part-time or full-time appointment. The following background requirements must be met:

- (a) The candidate must meet existing VA requirements for physicians, including credentialing and privileging requirements.
- (b) The candidate must present evidence of interest and involvement in research or teaching.
- (c) The candidate needs to qualify for a faculty appointment if the VA medical center is affiliated with a university.

NOTE: MS fellowship or related specialty training is strongly encouraged.

(2) **MS Regional Program Team.** The MS Regional Program Team composition must have adequate staffing to effectively meet Veterans' identified needs. All MS Regional Program staff must have their effort and responsibilities for the Regional MS Program documented as part of their credentialing process at their local VA medical facility. *NOTE: Staffing allocations and justification for these roles in an MS Regional Program are provided in (Appendix A).* The MS core team of an MS Regional Program will consist of the following individuals, but is not limited to the list below:

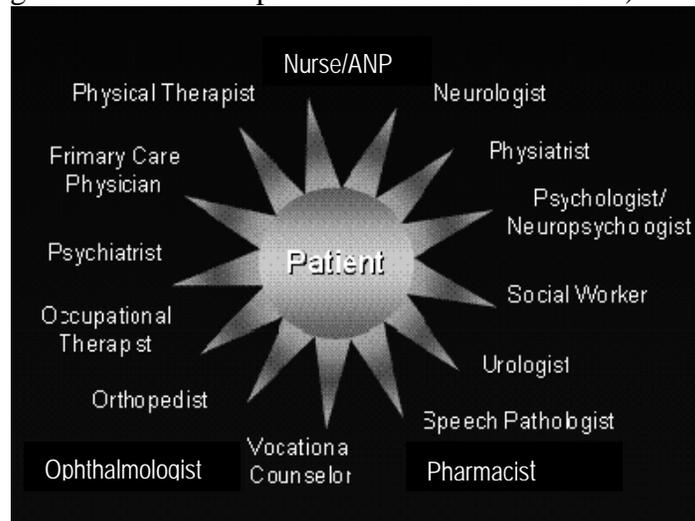
(a) **One Physician*** (Chief, MS Regional Program) with MS expertise assigned to direct the activities of the Regional MS Program.

(b) **One Nursing Staff Position*** to assist with MS treatment, case management, and education. All nurses need to have experience with MS and complete the training modules from the MSCoE. This individual will serve as the MS Regional Care Coordinator for the MS Regional Program. *NOTE: Mid-level practitioners, such as physician assistants or nurse practitioners, are ideally suited to serve as the MS Regional Care Coordinator. The expanded*

role of mid-level practitioners in the diagnosis and prescribing of medications can be helpful in the overall multidisciplinary management of large MS patient panels.

- (c) One Social Worker* assigned to serve the comprehensive social work needs of MS patients referred to the Regional MS Program.
- (d) One Administrative* Officer to assist with scheduling, telephone messages, and other administrative tasks of the Regional MS Program
- (e) Occupational therapists with MS experience serving inpatients and outpatients
- (f) Physical therapists with MS experience serving inpatients and outpatients
- (g) Other MS Regional Program Team members should include the following: pharmacists, dietitians, respiratory therapists, speech pathologists, recreation therapists, kinesiotherapists, psychologists, neuropsychologists, urologists, orthopedic surgeons, ophthalmologists, and chaplains. These health care specialists are important in multidisciplinary MS care and need to be knowledgeable about MS care. The overall multidisciplinary care of MS is demonstrated in Figure 1. **NOTE:** Positions marked (*) indicate the recommended minimum staff for an MS Regional Program.

Figure 1. Multidisciplinary MS Care (modified from International Organization of Multiple Sclerosis Nurses IOMSN)



(3) MS Regional Program Outpatient Services. The MS Regional Program’s outpatient clinic provides the full spectrum of health care to the local MS population.

- (a) Every MS Regional Program needs to provide an outpatient program of scheduled hours and treatment, including unscheduled visits for Veterans with acute conditions related to MS.
- (b) The scope of outpatient treatment at the MS Regional Programs needs to be comprehensive and multidisciplinary. Services provided to a particular individual are a part of a continuum of care and integrate inpatient and home care when needed.

(c) The MS Specialist must be able to successfully address the wide array of medical issues associated with the care of MS. However, consultations to other disciplines are often required to address the multifaceted problems of patients. Multidisciplinary care must be managed by the MS Regional Program team.

(4) **MS Regional Program Inpatient Services.** The MS Regional Programs provide the full spectrum of health care, but inpatient admission to the VA medical facility needs to be provided when appropriate. Inpatient admission needs to be considered for severe relapses, infections, or other serious illnesses related to MS. Inpatient services could include rehabilitation, acute and sub-acute medical and surgical care, mental health care, respite care, palliative care, and long-term care consistent with VHA policy.

(5) **MS Regional Program Quality Assurance.** Each MS Regional Program must undertake service-level quality improvement activities that monitor critical aspects of care and provide an on-going and continuous evaluation of the program to address patient access to care, patient satisfaction, patient outcomes, and risk management. If necessary, the program may redefine the systematic plan used for collecting and analyzing data, taking corrective action, and reporting results.

12. MS SUPPORT PROGRAMS

Facility Directors of any VA medical center caring for Veterans with MS and not designated as an MS Regional Program must have an MS Support Program as outlined below.

a. **MS Care Coordinator.** The Chief of Staff or Chief Medical Officer at each VA medical facility without a Regional MS Center must designate a staff member within the clinical services as the MS Care Coordinator. The individual selected as the MS Care Coordinator must have, or be willing to acquire, appropriate knowledge regarding:

- (1) MS treatment and rehabilitation;
- (2) Physical and psychosocial implications for the individual with MS and family;
- (3) Appropriate clinical and vocational interventions;
- (4) Prosthetic services for patients with MS;
- (5) VHA directives and benefits affecting Veterans with MS;
- (6) Community resources and services for the disabled;
- (7) Local peer counseling programs or groups; and
- (8) Federal laws or regulations regarding disability.

b. **MS Care Coordinator Communication and Training.** The name and location of the MS Care Coordinator must be posted on the VA medical facility Web site, in the Admissions and Ambulatory Care area, on all wards, and be listed in the medical facility telephone directory.

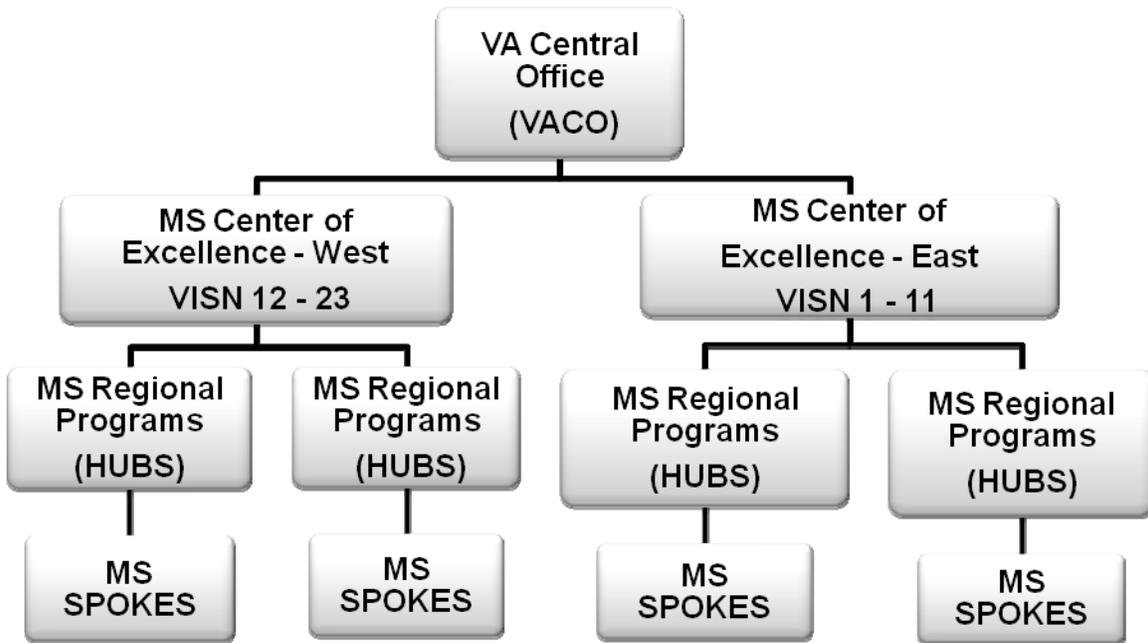
Arrangements need to be made for the designated MS Coordinator to receive specialized training through the VA MScOE-East or West.

c. **Appointment of MS Support Program Care Teams.** The facility Chief of Staff, or Chief Medical Officer, must appoint an MS Care Team at each VA medical facility without an MS Regional Program. The MS Primary Care Team at an MS Support Program needs to consist of a physician or group of physicians and the designated MS Care Coordinator. The MS Care Team must provide specialty care and consultative services to the local eligible Veteran patients with MS. Specialty MS care not available at the local VA medical facility needs to be performed by the MS Regional Program.

13. MSCOE HUB AND SPOKE NETWORK

Each VISN will have at least one MS Regional Program that will serve as a source for MS specialty consultation and education (see <http://www.va.gov/ms> for details). The primary care for individual MS patients will occur at their local VA medical facilities. MS support programs will exist in all VA medical facilities without a designated MS Regional Program. The MS Care Coordinators at each facility will assist with communication and referrals with the MS Regional Program.

Figure 2. MScOE Hub and Spoke Model



14. MS EDUCATION

The goal of MS education is to increase patient and provider knowledge, self-efficacy and access to resources. Patient and provider education are essential to the delivery of health care, early intervention, and patient compliance to treatment and rehabilitation. While the median age

of Veterans in the United States is about 60 years of age and most are male, the VA is now faced with providing care to a younger, more diverse generation, many whom will be seriously ill and or injured. As the demand for health care services increases, education for Veterans, their health care providers, families, and caregivers is an important and empowering resource.

a. **General MS Education.** There are many opportunities to learn about MS disease etiology, pathology, disease management, and the multidisciplinary care team approach. The MSCoE Web site (<http://www.va.gov/ms>) offers education materials and resources to both health care professionals and patients on current MS information regarding MS management, care recommendations, and services unique to VHA. The MSCoE are available for on-site training, mentoring, and consultation.

b. **Regional MS Care Coordinator Training.** Regional MS Care Coordinators may take advantage of day-long MS education symposia within their VISN that prepare RNs and non-nurse coordinators to sit for MS certification examination. The MS Certification for Nurses (MSCN) or MS Certification for Specialists (MSCS) provide formal recognition that is necessary to provide quality care to Veterans with MS and improves the standard of care level of the regional care team. MS education modules and online educational presentations are available to those unable to attend live meetings and symposia at <http://www.va.gov/ms>. Coordinators are encouraged to earn a minimum of 10 continuing education units (or specialty equivalent) per year related to MS treatments and/or management. Upon completion of the course(s), nurses and allied health care professionals will have obtained the knowledge and skills necessary to provide quality MS care.

c. **Educational opportunities within the MSCoE network.** The following are examples of, but not a finite list, of educational options. More information on these opportunities can be obtained by contacting the MSCoE. Recommended accredited MS educational opportunities and programs are:

(1) VA MSCoE Educational Events: teleconferences, Web-based, and face-to-face educational programs (refer to: <http://www.va.gov/ms>);

(2) VA MSCoE Directors and Coordinators Annual Regional meetings;

(3) VA MSCoE Symposia (Whitaker and Kroc Lectures);

(4) VA MSCoE Independent Studies and archived presentations;

(5) Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting;

(6) Americas Committee on Treatment and Research in MS (ACTRMS) Annual Meeting;

(7) European Committee on Treatment and Research in MS (ECTRMS) Annual Meeting;

(8) Latin American Committee on Treatment and Research in MS (LACTRIMS) Annual Meeting;

- (9) American Academy of Neurology (AAN) Annual Meeting;
- (10) Regional National Multiple Sclerosis Society-sponsored CME/CEU programs; and
- (11) International Organization of MS Nurses Regional Continuing Educational Credit Programs.

d. **Training of MS Regional Care Teams.** After 2 years of experience in MS care, it is recommended that the MS Care Coordinator take the exam for MS Certified Nurses (for RN's) (MSCN) or the MS Specialist Certification (for non RN coordinators) (MSCS). **NOTE:** For more information about MS nursing care go to the International Organization for MS Nurses Web site: <http://www.iomsn.org>. For more information about the certification exam, go to the Professional Testing Corporation Web site at <http://www.ptcny.com>.

(1) **Regional MS Program Chiefs.** See recommended accredited MS educational opportunities and programs (paragraph 14.c.).

(2) **Training of Providers at MS Support Programs.** See recommended accredited MS educational opportunities and programs (paragraph 14.c.).

15. REFERRAL GUIDELINES

The goal of the MS System of Care is to provide competent and convenient care to all Veterans with MS. For many patients this can be provided by their primary care provider in a local facility such as a CBOC. Situations that might require transfer of care, either temporarily (for consultation) or permanently, to a Regional MS Program include but are not limited to the following:

- a. Confirmation of a new diagnosis of MS;
- b. Evaluation of suspected MS where advanced diagnostic techniques are required;
- c. Counseling a newly diagnosed patient on treatment options;
- d. Managing complications of disease modifying therapies;
- e. Evaluation of treatment failure or conversion to progressive MS;
- f. Treatment with immunosuppressive medications; and
- g. Management of advanced progressive MS.

16. REFERENCES

- a. Bowling, A., Complimentary and Alternative Medicine and Multiple Sclerosis, 2nd edition, 2007, Demos Medical Publishing, New York, NY.

- b. Deloire, M.S.A., Bonnet, M.C., Salort, E., Arimone, Y., Boundineau, M., Petry, K.G., & Brochet, B. (2006). How to detect cognitive dysfunction at early stages of multiple sclerosis? *Multiple Sclerosis*, 12, 445-452.
- c. Fry, D., Pulmonary Function and Rehabilitation in Multiple Sclerosis. Clinical Bulletin. National MS Society, <http://www.nationalmssociety.org/download.aspx?id=164>, accessed 8/28/08.
- d. Khan, F., & Pallant, J. (2007). Chronic pain in multiple sclerosis: Prevalence, characteristics, and impact on quality of life in an Australian community cohort. *The Journal of Pain*, 8(8), 614-623.
- e. National MS Society. The palliative care continuum in multiple sclerosis. Available at: www.nmss.org/download.aspx?id=1027.
- f. Simon JH, Li D, Traboulsee A, Coyle PK, Arnold DL, et al. Standardized MR Imaging for Multiple Sclerosis: Consortium of MS Centers Consensus Guidelines. *AJNR* 2006;27:455-461.
- g. Wallin MT, Wilken JA, Turner AP, et al. Depression and MS. Review of a Lethal Combination. *JRRD*, 2006;43:45-62.
- h. Wallin MT, Wilken JA, Kane R. Cognitive dysfunction in MS. Assessment, Imaging and Risk Factors. *JRRD*, 2006;43:63-72.

VA MULTIPLE SCLEROSIS SYSTEM OF CARE
Multiple Sclerosis Centers of Excellence (MSCoE) Regional Centers
Staffing Calculations and Justification

Purpose: This staffing memorandum provides a recommendation for the number of clinical staff to manage Veterans with Multiple Sclerosis (MS) at a typical MSCoE Regional Center. These hub clinics along with their referral spoke clinics are critical to the delivery of MS care within each Veteran Integrated Service Network (VISN).

Background and Assumptions: Based on the 2006 National Ambulatory Medical Care Survey conducted by the National Center for Health Statistics, MS is the seventh most common disorder to be evaluated by neurology specialists, making up 6 percent of all referrals. Patients with MS have variable degrees of disability with complex symptoms and histories. The VA MS population is more disabled than the MS population in the private sector. The average MS disability is 0.5-1.0 points higher on the Patient Determined Disease Steps among Veterans with MS compared to non-Veterans. MS is a dynamic disease with relapses and remissions early in the course but ultimately progression in neurological disability ensuing in most individuals.

The calculations outlined below are based on the requirements of an average MS patient. It is recognized that MS patients have a range of needs from early mild cases that are not on disease modifying treatment to advanced patients with complications of quadriparesis and cognitive impairment. It is assumed that MS Regional Centers will have up to 50 percent advanced cases while spoke sites will have few such cases. The staffing estimates have been calculated in work hours per employee and converted into full time equivalent employees (FTEEs) based on the 2008 Office of Management and Budget estimates. These calculations were based in part on the health care staffing models for physicians, nurses and support staff outlined in the “Physician Staffing for the VA” published by the Institute of Medicine. Any significant deviations from this would require adjustments in staffing levels.

MSCoE Regional Center Director. The average MSCoE Regional Center site manages approximately 150 MS patients. Assuming that the average patient is seen by the director for 30 minutes in clinic every three months and that one hour of non clinic time is required for documentation, MSCoE registry follow-up, telephone calls and correspondence for every clinic visit, this would require a total of 900 (1.5 hours per patient visit x 4 patient visits per year x 150 patients = 900 patient hours per year) clinical hours per year. In addition, regional directors are required to assist spoke sites with patient management which would require approximately two hours per week or 96 hours per year. Total clinical time would be 996 hours per year.

In addition to clinical time, program directors have administrative and educational duties related to the MSCoE. Administrative duties would not only include local organizational work (approximately 2 hours per week or 96 hours per year) but monthly conference calls and attendance at yearly administrative meetings (48 hours per year).

Educational responsibilities would include participating in national education programs (48 hours per year) and local educational programs (one hour per week or 48 hours per year). Total administrative and educational commitment would be 240 hours.

In addition, all physicians have required educational and other employment related duties, including outpatient and inpatient clinical coverage, teaching duties related to affiliated medical school, research, and service on local committees which total at least 16 hours per week or 768 hours per year.

*Regional Center Director total time commitment = 2,004 hours/year
or 1.0 FTEE per 150 MS patients*

MSCoE Regional Center Nurse Coordinator. Assuming 150 MS patients and the visit levels discussed above, the nurse spends 15 minutes of face-to-face time with each patient in clinic as well as two hours of non clinic time for each clinic visit, a total of 1350 clinical hours (2.25 hrs/patient visit x 4 patient visits per year x 150 patients = 1350 patient hours per year) per year would be required. In addition nurse coordinators are required to assist the Regional MS Center and spoke sites with delivery of MS disease modifying treatments which would require approximately three hours per week or 144 hours per year. Total clinical time would be 1446 hours per year.

In addition to clinical time, nurse coordinators have administrative and educational duties related to the MSCoE program. These would include local organizational work (2 hours per week or 96 hours per year), monthly conference calls and attendance at yearly administrative meetings (48 hours per year). Educational responsibilities would include participating in national educational programs (48 hours per year) and local educational programs (one hour per week or 48 hours per year). Total administrative and educational time would be 240 hours per year.

All nurses have local clinical duties, training requirements, and administrative duties such as service on hospital committees that require an additional 384 hours per year.

*Regional Center Nurse Coordinator total time commitment = 2,118 hours per year
or 1.0 FTEE per 150 MS patients*

MSCoE Regional Center Social Worker. Social work services are an integral part of the overall VHA health care program and the MS Continuum of Care. Social Work services provide help to Veterans and their families in resolving the psychosocial, emotional and economic problems associated with the stresses of illness. Because MS related disability strikes in the early adult years, there are frequently acute occupational, home and family issues to address. Social workers bring skills in individual, group, and family treatment to the care of Veteran patients as they move through outpatient clinic, hospitalization and post-hospital care back into the community. They provide a major link between the VHA health care system and the community through the development and utilization of community resources and VA services in support of established treatment goals for Veterans and their families.

Assuming 150 MS patients in the average MS Regional Center and the visit levels discussed above, a social worker will spend approximately 60 minutes face-to-face time with each patient and two hours of follow-up per year (450 hours per year) related to outpatient and home related concerns.

The MS Regional Center social worker will assist with coordinating discharge planning for all MS patients admitted to the hospital including referral services and accessing and coordinating community resources. It is estimated that 25 percent of the MS population will be admitted to the hospital, rehabilitation facility, or nursing home at some point in any given year with a minimum of two hours required for each admission (150 hours per year).

Monitoring functional needs, mental health needs, and health issues related to chronic disabilities will be critical and require individual attention and specific referral to both VA and community programs (450 hours per year). Involvement in research and educational related activities that overlap with the social work will require additional time (550 hours per year).

Additional duties of the MSCoE Regional Center social worker will include updating the MSCoE Clinical Surveillance Tool on each MS patient in the center with data provided by the director and nurse (150 hours per year). Coordination and delivery of programs related to MS patient support (MS groups), caregivers, and community resources will take approximately two hours per week (96 hours per year).

Social workers will have local training requirements and administrative duties such as service on hospital committees that require 4 hours/week for an additional 192 hours per year.

*Regional Center Social Worker total time commitment = 2,038 hours per year
or 1.0 FTEE per 150 MS patients*

MSCoE Regional Center Administrative Officer. Assuming 150 MS patients and the visit levels discussed above, estimated averages for each patient visit were estimated to calculate yearly totals. The Program Assistant spends an average of 1 hour annually per patient to call or mail multidisciplinary appointments and set-up travel, 15 minutes to schedule the appointments in CPRS, 30 minutes for incoming calls to refer to nursing or answer questions, 15 minutes for appointment reminder calls, 15 minutes for unscheduled office visits (i.e., for questions, forms, prescriptions), 15 minutes to communicate with clinical staff, 30 minutes for required administrative monitoring (i.e., workload tracking, report generation), 30 minutes for VA Benefits and Fee Basis coordination. An additional 1 hour per week is required to perform faxing, scanning and photocopying for clinical, educational and administrative tasks. Total administrative time would be 750 hours per year.

The administrative coordinator will be responsible for arranging multidisciplinary evaluations related to the diagnosis of MS and MS exacerbations for individual Veterans (500 hours per year). The coordinator will be responsible for assembling the MS team for treatment planning and coordination conferences related to Veteran's care needs (250 hours per year) and administering the clinics quality improvement initiatives (250 hours per year).

In addition, all VA employees have local training requirements and administrative duties such as service on hospital committees that require 4 hours per week for an additional 192 hours per year.

MSCoE Regional Center Staff Summary Table*

<i>Staff Position</i>	<i>Hours per year</i>	<i>Annual FTEE</i>
Director (MD)	2,004	1.0
Nursing Coordinator (RN or NP)	2,118	1.0
Social Worker (MSW)	2,038	1.0
Administrative Officer	1,942	1.0

*Based on 150 MS patients

Reference: Lo AC, Hadjimichael O, Vollmer TL. Treatment patterns of multiple sclerosis patients: a comparison of Veterans and non-Veterans using the NARCOMS registry. Mult Scler 2005;11(1):33-40.

**COMPUTERIZED PATIENT RECORDS SYSTEM (CPRS)
MSCOE PROGRESS NOTE TEMPLATE**

HISTORY OF PRESENT ILLNESS:

Year of onset:

MULTIPLE SCLEROSIS REVIEW OF SYSTEMS:

Cognitive Slowing:

Depression:

Anxiety:

Emotional Lability:

Fatigue:

Heat Intolerance:

Ataxia:

Weakness:

L'Hermitte's Phenomenon:

Spasticity:

Pain/Dysesthesias:

Trigeminal Neuralgia:

Tonic Spasms:

Seizures

Seizures:

 Seizure Description:

 Year onset: Frequency:

 Date of last seizure:

 Medication hx:

 EEG:

Tonic seizure:

Diplopia:

Swallowing Difficulty:

Vertigo:

Bladder Problems:

Bowel Problems:

Sexual Problems:

GENERAL MEDICINE REVIEW OF SYSTEMS:

Constitutional:

Eyes:

Ears:

Nose:

Mouth/Dental:

Breast:

Cardiac:

Respiratory:

GI/Digestive:

GENERAL MEDICINE REVIEW OF SYSTEMS:

GU/Urologic:
Blood/Lymphatic:
Endocrine:
Musculoskeletal:
Skin:

MEDICATIONS:

Multiple Sclerosis Medications:
Avonex:
Betaseron:
Copaxone:
Rebif:
Mitoxantrone:
Other:
Comments:

Multiple Sclerosis Medications:

ACTIVE MEDICATIONS:

PAST MEDICAL HISTORY:

SOCIAL HISTORY:

Habits:
Employment History:
Marital History:
Educational History:
Living Arrangement:
Military:
Dates of military service:

Service connected for Multiple Sclerosis: Yes

FAMILY HISTORY:

Grandparents:
Aunt/Uncle:
Father:
Mother:
Sibling(s):
Children:

GENERAL EXAMINATION:

Weight:
BMI:
Blood Pressure:
Pulse:
Temp:
Resp:
Pain Score:

NEUROLOGIC EXAMINATION:

Mental Status Examination:

Cranial Nerves:

II:

III, IV, VI:

V:

VII:

VIII:

IX, X:

XI:

XII:

Motor:

Strength:

Confrontational Strength Testing:

Individual components:

D R: /5 L: /5

B R: /5 L: /5

T R: /5 L: /5

EC R: /5 L: /5

IO R: /5 L: /5

IP R: /5 L: /5

Q R: /5 L: /5

H R: /5 L: /5

G R: /5 L: /5

AT R: /5 L: /5

EHL R: /5 L: /5

PER R: /5 L: /5

NEUROLOGIC EXAMINATION:

D = Shoulder Abductors > 90 Degrees

T = Elbow Extensors

B = Elbow Flexors

EC = Wrist Extensors

FC = Wrist Flexors

ED = Finger Extensors

FD = Finger Flexors

IP = Hip Flexors

H = Knee Flexors

AT = Ankle Dorsi Flexors

G = Ankle Plantar Flexors

Tone:

Bulk:

9 hole peg test: R: seconds; L: seconds.

Deep Tendon Reflexes:

Triceps R: /4 L: /4

APPENDIX B

Biceps R: /4 L: /4
Brachioradialis R: /4 L: /4
Patellar R: /4 L: /4
Ankle R: /4 L: /4
Plantar responses: R: L:
Ankle clonus (beats) R: L:

Coordination:
Tremor:
Finger to nose:
Heel to shin:
Sensory:
Vibration:
Position sense:
Pin/Temperature:

Gait:
25 foot timed walk: seconds

Urine Output:
Urine volume voided today: ml.
Post void residual urine today: ml.

DIAGNOSTIC DATA:

Imaging Data:
MRI Brain with enhancement: Year:
MRI Brain without enhancement: Year:
MRI Thoracic Spine: Year:
MRI Lumbosacral Spine: Year:
MRI Cervical Spine: Year:
CSF STUDIES: Year:
Normal, Significant findings:

Culture and Sensitivity/Gram Stain:
Normal, Significant findings:
Cell Count: Normal, Significant findings:
Glucose: Normal, Significant findings:
Protein: Normal, Significant findings:
Oligoclonal Banding: Normal, Significant findings:
IgG Synthesis Rate: Normal, Significant findings:
IgG Index: Normal, Significant findings:
Fungal Culture: Normal, Significant findings:
AFB Culture: Normal, Significant findings:
CMV Culture: Normal:
PCR Herpes: Normal, Significant findings:
Cryptococcal Antigen: Normal, Significant findings:
VDRL: Normal, Significant findings:

Other:
VEP/BAEP:

Visual Evoked Potentials: Year:
Normal, Significant findings:
Brainstem Evoked Potentials: Year:
Normal, Significant findings:
Laboratory diagnostic data (Serum):
Historical Lab Data:
1 year of data:
4 years of data:
Angiotensin Converting Enzyme (ACE):
Anti HTLV I/II:
Anti Nuclear Antibody (ANA):
Anticardiolipin Antibodies (ACLA):
B12:
CBC w/Diff:
Extractible Nuclear Antigen (ENA):
Human Immunodeficiency Virus (HIV) Antibody:

DIAGNOSTIC DATA:

Liver Panel:
Lyme Disease Serology:
Sjogren's Antibody A (SSA):
Sjogren's Antibody B (SSB):
TSH:
VDRL:
Other:

NEUROLOGIC DIAGNOSIS:

Multiple Sclerosis, Relapsing Remitting (RRMS):
Multiple Sclerosis, Secondary Progressive (SPMS):
Multiple Sclerosis, Primary Progressive (PPMS):
Clinically Isolated Syndrome:

AMBULATION/FUNCTIONAL CAPACITY:

Ambulation capacity:
Ambulates without support greater than 25 feet.,
Ambulates with unilateral support greater than 25 feet.,
Ambulates with bilateral support greater than 25 feet.,
Ambulates with bilateral support less than 25 feet.,
Limited to wheelchair with functional use of arms.,
Limited to wheelchair without functional use of arms.

Disability Rating Scale
Modified Kurtzke expanded disability status score:
10 - Death due to MS.

MS Disease Steps Scale:
(U) Unclassifiable
European Database Scale (EDMUS)
10 - Death due to MS.

DISCUSSION:

Initial symptoms and subsequent course:

McDonald Diagnostic Criteria

Patient meets McDonald Diagnostic Criteria (Ann Neurol 2001; 50: 121-127) for clinically definite MS with two or more clinical attacks and two or more objective clinical lesions.

Patient meets McDonald Diagnostic Criteria (Ann Neurol 2001; 50:121-127) for clinically definite MS with two or more clinical attacks and one objective clinical lesion.

Paraclinical evidence of second lesion, with disease dissemination in space, is evident on brain MRI as follows:

Patient meets McDonald Diagnostic Criteria (Ann Neurol 2001; 50: 121-127) for clinically definite MS with one clinical attack and two or more objective clinical lesions. Paraclinical evidence for dissemination in time (second attack) demonstrated by a subsequent brain MRI
MS MDC CRITERIA 4.

Patient meets McDonald Diagnostic Criteria (Ann Neurol 2001; 50:121-127) for clinically definite MS, with one clinical attack and one clinical lesion. Paraclinical evidence of second lesion, with disease dissemination in space, is evident on brain MRI, as follows:

Patient meets McDonald Diagnostic Criteria (Ann Neurol 2001; 50:121-127) for clinically definite primary progressive MS, with positive CSF, and evidence of dissemination of disease in space and time.

McDonald Criteria Guidelines (Ann Neurol 2001; 50:121-127), Most disabling MS symptoms:

- 1.
- 2.
- 3.
- 4.
- 5.

Fatigue severity scale: 7.

Fatigue Severity Score Web site

Beck Depression Inventory: /63

Estimate of Vocational Capacity:

Comments:

In an 8-hour workday, number of hours patient can:

Sit:

Stand:

Walk:

Work:

(Work = sitting, standing, or walking)

How often patient can lift 10 pounds:

How often patient can carry 10 pounds:

Patient can repeatedly use hands to grasp, push, pull, manipulate objects:

Right: Yes

Left: Yes

Patient can use feet for repetitive movements as in operating foot controls:

Right: Yes

Left: Yes

Patient is able to:

Bend:

Squat:

Crawl:

Climb:

Stoop:

Reach above:

Crouch:

Kneel:

Pain

Location (check all that apply):

Severity of pain:

Mild (awareness but no handicap).

Slight (could be tolerated but some handicap in the performance).

Moderate (could be tolerated but marked handicap in the performance).

Severe (would preclude activity precipitating the pain).

Summary of disability assessment:

Patient demonstrates significant and persistent disorganization of motor function in two extremities, resulting in sustained disturbance of gross and dexterous movement, or gait and station. Significant, reproducible fatigue of motor function with substantial muscle weakness on repetitive activity, demonstrated on physical examination, resulting from neurological dysfunction in areas of the central nervous system known to be pathologically involved by the multiple sclerosis process.

The degree of interference with locomotion and/or interference with the use of fingers, hands, and arms is: Visual impairment is Exam shows: Visual acuity in the better eye after best correction is 20/200 or less, Internuclear ophthalmoplegia.

Disease modifying management recommendations:

Symptom management recommendations:

PLAN:

Case staffed: MD.

Imaging Ordered: MRI Brain with Enhancement, MRI Brain without Enhancement, MRI T-Spine, MRI L-Spine, MRI C-Spine, Other:

Laboratory Studies:

Other:

CFS Studies Ordered:

Culture and sensitivity/gram stain, Cell count, Glucose, Protein (omit if ordering IgG Index), Oligoclonal banding, IgG synthesis rate (includes IgG), IgG index (includes albumin, IgG, CSF tot protein, CSF IgG, CSF pro electrophoresis), Fungal culture, AFB culture, CMV culture, PCR Herpes, Cryptococcal antigen, VDRL, Other:

Consultation Orders:

Disease modifying medications:

Axonex (Interferon Beta 1A, 30mcg IM Q 1/week), Betaseron (Interferon Beta 1B, 0.25mg SC QOD), Copaxone (Glatimir Acetate, 20mg SC QD), Rebif (Interferon Beta 1A, 44mcg SC Q 3/wee), Novantrone (Mitoxantrone, consult Hem/Onc), Hem/Onc Consultation, Other:

Symptomatic medications:

Patient Education:

Handout(s):

Patient advised to contact MS websites:

National Multiple Sclerosis Society

National Multiple Sclerosis Society website

Paralyzed Veterans of America

PVA Web site

VA MS Centers of Excellence

Clinic Nurse to follow up:

Arrange patient teaching for administration of DMT medication.

Coordinate admission to Short Stay Unit (SSCU) for lumbar puncture.

Mail patient educational material, Telephone patient in (weeks) to discuss: Follow up clinic appointment: Discharged from clinic, RTC after CNS imaging completed, RTC in

MEDICATION RECONCILIATION:

The process of medication reconciliation was completed during today's visit. The Veteran's current medications (including non-VA medications and any changes made today) were reviewed with the patient and/or caregiver. A written list was offered and/or provided.

MSCOE CLINICAL DATA SURVEILLANCE (CDS) TOOL

CORE CLINICAL QUESTIONS (1-6)

1) Race as defined by VA (fill out once):

- American Indian or Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or other Pacific Islander
- White
- Other: _____

2) Ethnicity as defined by VA (fill out once): Hispanic Not Hispanic

3) MS Diagnosis (based on the McDonald Criteria, Ann Neurol 2005; 58:840):

a) MS Possible MS Clinically Isolated Syndrome Rule-out MS

b) Month & year of first neurologic sign or symptom: ___/___ Year of MS diagnosis: _____

c) Type of initial MS symptom (check all that apply; fill out once):

- Motor
- Sensory
- Brainstem
- Cerebellar
- Optic neuritis
- Cognitive
- Bowel/Bladder
- Spinal cord
- Other: _____

4) Multiple Sclerosis Subtype:

- Relapsing-Remitting
- Secondary Progressive, Year of transition to secondary progressive MS: _____
- Primary Progressive
- Progressive-Relapsing
- Neuromyelitis Optica/Devic's Disease

5) MS Disability:

a) Number of relapses* over the past 12 months: _____

*relapse: worsening neurological symptoms for > 24 hours that stabilize or resolve

b) Year patient reached an EDMUS/Kurtzke DSS disability score of 6 (walks with unilateral or bilateral support): _____

c) Year patient reached EDMUS/Kurtzke DSS disability score of 8 (restricted to chair): _____

d) Current MS Disability (check one box):

Check appropriate box:	EDMUS/Kurtzke DSS ¹ Grading Scale	Disability Description
<input type="checkbox"/>	0	Normal findings on neurological examination
<input type="checkbox"/>	1	No disability, minimal signs on neurological examination
<input type="checkbox"/>	2	Minimal and no ambulation-related disability, able to run
<input type="checkbox"/>	3	Unlimited walking distance without rest, but unable to run; or a significant no ambulation-related disability
<input type="checkbox"/>	4	Walks without aid, limited walking distance, but >500 meters without rest.
<input type="checkbox"/>	5	Walks without aid, walking distance <500 meters without rest
<input type="checkbox"/>	6	Walks with unilateral or bilateral support, walking distance <100 meters without rest
<input type="checkbox"/>	7	Home restricted, a few steps with wall or furniture assistance, walking distance <10 meters without rest
<input type="checkbox"/>	8	Chair restricted, unable to take a step. Some effective use of arms
<input type="checkbox"/>	9	Bedridden and totally helpless
<input type="checkbox"/>	10	Death due to MS

¹European Database for MS Grading Scale-Kurtzke DSS, adapted from Grimaud J, Multiple Sclerosis 1999;5:234-238.

6) MS Medications:

Which of the following MS disease modifying agents are you using now or have you used in the past. Check all that apply and list how many years on drug prior to entering VA health care system:

Medication Name	Using Now	Used in past prior to entering VA	# years on medication prior to entering VA
Avonex (interferon beta-1a)			
Betaseron (interferon beta-1b)			
Rebif (Interferon beta-1a)			
Copaxone (glatiramer acetate)			
Novantrone (mitoxantrone)			
Tysabri (natalizumab)			
Corticosteroids (e.g. methylprednisolone, prednisone)			
Other:			

ABBREVIATIONS

<i>Abbreviation</i>	<i>Definition</i>
CAM	Complementary and Alternative Medicine
CCHT	Care Coordination Home Telehealth
CMSC	Consortium of Multiple Sclerosis Centers
CDS Tool	Clinical Data Surveillance Tool
CNS	Central nervous system
CPRS	Computerized Patient Record System
DMT	Disease modifying therapy
EDSS	Expanded Disability Status Scale
EMT	expiratory muscle weakness
FSS	Functional System Score
HIV	Human Immunodeficiency Virus
HTLV I/II	Human T-lymphocyte Virus
IMT	inspiratory muscle weakness
MACFIMS	Minimal Assessment of Cognitive Function in Multiple Sclerosis
MS	Multiple Sclerosis
MSCN	Certification MS certified nurse
MSCoE	Multiple Sclerosis Center of Excellence
MSCS	MS Specialist Certification
MSQLI	Multiple Sclerosis Quality of Life Index
PP MS	Primary progressive MS
OCT	optical coherence tomography
PBM	Pharmacy Benefits Management
PR MS	Progressive relapsing MS
PTSD	Post Traumatic Stress Disorder
PVR	post void residual
RR MS	Relapsing-remitting MS
SP MS	Secondary progressive MS
TENS	Transcutaneous Electrical Nerve Stimulation
VA MEDICAL CENTER	Veterans Affairs Medical Center
VDRL	Venereal Disease Research Laboratory
VEP	visual evoked potentials
VERA	Veteran Equitable Resource Allocation
VHA	Veterans Health Administration
VISN	Veteran Integrated Service Network

WEB-BASED RESOURCES**Veterans Affairs MS Centers of Excellence**

Established by the Department of Veterans, these centers are organized around four functional cores: (1) clinical care, (2) research and development, (3) education and training, and (4) informatics and telemedicine

www.va.gov/ms

VA Pharmacy Benefits Management

<http://vaww.pbm.va.gov> *NOTE: This is an internal VA web site, not available to the public.*

Center for Disease Control and Prevention

<http://www.cdc.gov/mmwr/PDF/wk/mm5753-Immunization.pdf>

Veterans Equitable Resource Allocation

http://vaww.arc.med.va.gov/references/faqs/faqs/faq_11.html *NOTE: This is an internal VA web site and is not available to the public.*

McDonald MS Diagnostic Criteria

www.mult-sclerosis.org/DiagnosticCriteria.html

Kurtzke Expanded Disability Status Scale

<http://www.mult-sclerosis.org/expandeddisabilitystatusscale.html>

Fatigue Severity Scale

<http://www.mult-sclerosis.org/fatigueseverityscale.html>

Consortium of Multiple Sclerosis Centers (CMSC) MRI protocol

<http://www.ms-care.org/cmssc/images/pdf/MRIprotocol2003.pdf>

Standardized MR Imaging Protocol for Multiple Sclerosis: Consortium of MS Centers Consensus Guidelines

<http://www.ajnr.org/cgi/content/full/27/2/455>

ADA Home Page

Information and technical assistance on the Americans with Disabilities Act

www.usdoj.gov/crt/ada

Medicare Information

Official agency web site of the Centers for Medicare & Medicaid Services (CMS)

<http://cms.hhs.gov/>

National Center for Complementary and Alternative Medicine (NCCAM)

Exploring complementary and alternative healing practices in the context of rigorous science, training researchers, and disseminating authoritative information to the public and professionals.

<http://nccam.nih.gov/>

National Institute of Neurological Disorders and Stroke

News, funding information, studies that seek patients, and more. Accessible version of web site available

www.ninds.nih.gov/

National Library of Medicine

Large medical library on health information, library services, and more

www.nlm.nih.gov/

Social Security Online

www.ssa.gov/

Center for Medicare Advocacy

Resource for anyone sorting through the complexities of Medicare

www.medicareadvocacy.org/

National Organization for Rare Disorders

Includes three searchable databases and index on rare diseases

www.rarediseases.org/

MS Medications

Novantrone® www.novantrone.com/

Betaseron® www.betaseron.com/

Avonex® www.avonex.com/

Tysabri® www.tysabri.com/

Rebif® www.rebif.com/

Copaxone® www.copaxone.com/

AbilityHub

Assistive technology for people with a disability who find operating a computer difficult, maybe even impossible. Offers adaptive equipment and alternative methods available for accessing computers www.abilityhub.com/

Apple Computer Accessibility

Helps people with special needs attain independence through personal computers

www.apple.com/accessibility

IBM Accessibility Center

Product and service information for people with disabilities

www-306.ibm.com/able

Microsoft Accessibility Technology for Everyone

Includes information about built-in accessibility features in Microsoft products that can be adjusted to meet an individual's needs and preferences

www.microsoft.com/enable

ABLEDATA

Information on assistive technology and rehabilitation equipment. Web site has full graphics and low graphics options

www.abledata.com/

Disabled Online

Providing beneficial resources for the disabled community and their families and friends, including news stories, message boards, disabled topics and chat rooms

www.disabledonline.com

The Home Wheelchair Ramp Project

Manual of design and construction for modular wheelchair ramps

www.wheelchairramp.org/

American Academy of Neurology (AAN)

Worldwide professional association dedicated to those with neurological disorders

www.aan.com/public

CenterWatch Clinical Trials Listing Service™

Information on clinical research, clinical trials, and more. Separate sections for patients and industry professionals

www.centerwatch.com/

Lotsa Helping Hands—When friends & family need help

Web service with easy-to-use, private group calendar, specifically designed for organizing helpers, where everyone can pitch in

<http://nmss.lotsahelpinghands.com/>

National Family Caregivers Association

For those who care for chronically ill, aged, or disabled loved ones

www.thefamilycaregiver.org/

Mercy Medical Airlift of the National Patient Travel Center

A non-profit organization that helps to provide and make referrals for free air transportation for people who cannot afford to get to distant medical centers and disease-specific clinical centers
800-296-1217

www.mercymedical.org/

NARIC: The National Rehabilitation Information Center

Visitors can submit requests, search database, read RehabWire, explore research from the National Institute on Disability and Rehabilitation, and more
www.naric.com/

Professional Internet Resources

American Neurological Association (ANA)

Information about the association's events, publications, and history. Site also serves as forum for academic neurology
www.aneuroa.org/

Consortium of MS Centers (CMSC)

Organized in 1986 under the direction of neurologists interested in the clinical care of multiple sclerosis, CMSC has grown to become a multi-disciplinary organization providing a team approach to MS care and a network for all health care professionals and others specializing in the care of persons with MS
www.ms-care.org/

Curbside.MD

A medical search engine that provides evidence-based answers to naturally-phrased neurological questions. Categories include Visual Diagnosis, Guidelines and recommendations, Clinical Trial Outcomes, Review Articles
www.curbside.md/

International Organization of MS Nurses (IOMSN)

The first and only international organization focused solely on the need and goals of professional nurses who care for people with multiple sclerosis
www.iomsn.org/

Medscape

Major provider of digital health records and online health information. Their website offers a news publication, as well as specialty-specific home pages for physicians and nurses
www.medscape.com

Medscape Today

www.medscape.com/medscapetodayhome

Neurology and Neurosurgery

www.medscape.com/neurologyhome

Psychiatry and Mental Health

www.medscape.com/psychiatryhome

Nurses

www.medscape.com/nurseshome

Multiple Sclerosis International Federation (MSIF)

International body linking the activities of National MS Societies around the world

www.msif.org/en/

Atlas of MS Database

Information and data on the epidemiology of MS and the availability and accessibility of resources to diagnose, inform, treat, support, manage and rehabilitate people with MS worldwide are available in one database for analysis and comparison at country, regional, and global levels

www.atlasofms.org/

National Library of Medicine

World's largest medical library

www.nlm.nih.gov

Paralyzed Veterans of America (PVA)

The PVA is a congressionally chartered Veterans service organization dedicated to the special needs of Veterans with spinal cord dysfunction. Services include research and education, programs for professionals, and publications

www.pva.org

The PVA produces **clinical practice guidelines** developed by the Multiple Sclerosis Council, as well as an **online catalog**.

Organizations | Journals

Neurology—Official journal of the American Academy of Neurology

www.neurology.org/

Annals of Neurology

www3.interscience.wiley.com/anon.html

Archives of Neurology

<http://archneur.ama-assn.org/>

International Journal of MS Care—Official publication of the CMSC

<http://www.msicare.org>

Journal of Neurology, Neurosurgery, and Psychiatry

<http://jnnp.bmjournals.com/>

Journal of Neuroimmunology

www.journals.elsevierhealth.com/periodicals/jni/current

Journal of the Neurological Sciences

www.journals.elsevierhealth.com/periodicals/jns/home

The Lancet

www.thelancet.com/

The Lancet Neurology

www.thelancet.com/journals/laneur/current

Multiple Sclerosis

www.ingentaconnect.com/

Neurotherapeutics (October 2007 issue focuses on MS)

www.neurorx.org/