

**VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE
PROGRAM GUIDE
MUTLIPLE SCLEROSIS SYSTEM OF CARE PROCEDURES**

1. REASON FOR ISSUE

This VHA Program Guide describes the origins of, essential components of, and procedures of the VA Multiple Sclerosis Centers of Excellence (MSCoE) program, which is designed to ensure that all enrolled Veterans, wherever they live, have access to high quality MS care. It accompanies VHA Directive 1011.06 Multiple Sclerosis System of Care.

2. BACKGROUND

MS is a unique disease in the VA system due to its onset in young adulthood, female predilection, and common connection with military service. MS can be difficult to diagnose due to its variable presentations. It is also challenging to manage due to a dynamic and unpredictable course, progressive nature, variable symptoms, multiple treatments with potentially life-threatening adverse effects, the need for costly monitoring for effectiveness, and increasing disability over essentially a normal life span. To adequately care for Veterans with MS requires a multidisciplinary team, including neurologists, physiatrists, psychologists, internists, primary care providers, nurses, social workers, rehabilitation therapists, urologists, and other providers who are knowledgeable about the care of MS.

A. To address the unique needs of the Veteran MS population, in 2001, Congress urged the VHA to establish two MSCoE for clinical care, education, and research [Conference report (H. Rept. 106-988), Senate Appropriations Committee Report (H. Rept. 106-674) that accompanied Department of Veterans Affairs (VA) 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 and supporting local facilities and providers. In 2002, based on competitive applications, two centers were selected. One center is located at the VA Medical Center in Baltimore, MD, in Veteran Integrated Service Network (VISN) 5, serving VISNs 1–10. The second center is co-located at the VA Medical Centers in Seattle, WA and Portland, OR, in VISN 20, serving VISNs 12–23. The MSCoE were made permanent by “The Veteran’s Benefits, Healthcare and Information Technology Act of 2006.”

B. The MSCoE structure and core functions include expert care initiatives, evidence-based recommendations, other programs directed at enhancing the quality of MS care, and education for providers and Veterans. A hub and spoke model of MS Regional Programs and MS Support Programs has been established for referrals within each VISN. MSCoE Programs will maximize the use of VA’s

electronic medical record and the VHA Corporate Data Warehouse (CDW), VA national clinical databases, including the MS Assessment Tool and MS Surveillance Registry (MSSR), VHA MS Center of Excellence Data Repository using the CDW, and other databases for clinical, administrative, research, and telehealth resources to improve care coordination quality, access, and efficiency.

3. RESPONSIBLE OFFICE

The Office of Specialty Care Services (10P11) is responsible for the contents of this Program Guide. Questions may be referred to the National Director of Neurology Services.

4. REVIEW

This MSCoE Program Guide is scheduled for review with the renewal of the MS System of Care VHA Directive 1011.06 or every five years. Changes or updates may occur earlier in case of major practice or medication changes.

Mitchell Wallin, MD, MPH
Director, MSCoE-East

Jodie Haselkorn, MD, MPH
Director, MSCoE-West

Michelle Cameron, MD, PT, MCR
Co-Director, MSCoE-West

CONTENTS

ITEM	PAGE
1. RESPONSIBILITIES	1
2. NATIONAL SYSTEM OF MS CARE	2
3. POPULATION SERVED	3
4. MS REGIONAL AND SUPPORT PROGRAMS	3
5. MS SYSTEM OF CARE CONTINUUM	5
6. HEALTH MANAGEMENT ISSUES THROUGH THE CONTINUUM OF CARE	7
7. MS EDUCATION	9
8. RESEARCH	10
9. REFERENCES	10

MULTIPLE SCLEROSIS SYSTEM OF CARE PROCEDURES

This Program Guide outlines specific details on the structure, function, and interaction of the MSCoE and the network of clinicians providing care for Veterans with MS. It does not include a description of comprehensive MS treatments and services across the continuum of MS disability.

The MSCoE have been charged with improving the care provided to Veterans with MS without changing the setting of care. The MSCoE also monitor the VHA MS population and its care needs.

1. RESPONSIBILITIES

A. **Chief Officer for Specialty Care Services:** The Chief Officer for Specialty Care Services is responsible for developing and maintaining policies and procedures, working with the National Director of Neurology Services to ensure high quality subspecialty MS care, and for ensuring oversight of the MSCoE.

B. **National Director of Neurology Services:** The National Director of Neurology Services is responsible for developing and maintaining policies and procedures, working with the MSCoE Directors to ensure high quality subspecialty MS care, and providing oversight for the MSCoE. As such, the National Director of Neurology Services is responsible for approving an oversight plan within the MSCoE as outlined in the *Center of Excellence Government Accountability Office (GAO) report number 16-54, Centers of Excellence: DOD and VA Need Better Documentation of Oversight Procedures*. This GAO report recommends a periodic independent review of VA Centers of Excellence. (VHA Directive 1215, Standards for Veterans Health Administration Centers of Excellence). The National Director of Neurology Services recognizes that local and regional issues need consideration in the implementation of the directive and will serve as the communication liaison and subject matter expert to VA Central Office, VISN leadership, and local VA medical facilities.

C. **Multiple Sclerosis Centers of Excellence Directors:** MSCoE Directors are responsible for supporting the National Director of Neurology Services and the Chief Officer for Specialty Care Services in developing and maintaining policies and procedures for high quality MS care. MSCoE Directors are responsible for identifying advances in MS care, gaps in care, and making recommendations to appropriate VA Central Office program offices. MSCoE Directors provide recommendations to the National Director of Neurology Services regarding VA medical facility-based care and the coordination of MS care, as well as providing expertise and education for health care providers, Veterans, and caregivers. MSCoE Directors are responsible for promoting informatics-based approaches and telehealth (e.g., e-consults and clinical video telehealth) to MS specialists. MSCoE Directors are responsible for designating MS Regional Programs and MS Support Programs.

D. **VISN Directors:** VISN Directors are responsible for allocating adequate resources to ensure high quality MS subspecialty care. This includes supporting MS

Regional Programs and MS Support Programs as defined below. The VISN Director is responsible for ensuring that MS care is delivered by qualified, competent staff.

E. **VA Medical Facility Directors:** VA medical facility Directors are responsible for ensuring that there are adequate resources to provide high quality MS subspecialty care. VA medical facility Directors at facilities providing care to more than 100 Veterans with MS and with access to appropriate inpatient and outpatient services, are encouraged to provide adequate space and staffing for MS care in their facility for an MS Regional Program, if designated. Other VA medical facilities are recommended to have an MS Support Program. VA medical facility Directors with MS Regional Programs are encouraged to work with the MSCoE in the staffing and oversight of these programs.

F. **MS Regional Program Directors:** The MS Regional Program Directors work with their local VA medical facility Director and the MSCoE to implement a system of comprehensive care for Veterans with MS in their VISN or portion of the VISN if more than one Regional Program exists in a VISN. The MS Regional Program Directors provide for the annual evaluations, surveillance of Veterans in their catchment area, monitor outcomes and risk management, undertake service level-quality improvement activities, and participate in MSCoE educational programs. The MS Regional Program staff are expected to be actively engaged in MSCoE national activities.

G. **Regional MS Program Coordinators:** MS Regional Program Coordinators are responsible for assisting MS Regional Program Directors with the organization and clinical operation of the Regional MS Clinic. They help facilitate the coordination of clinical and educational services with the MS Support Programs.

H. **Multiple Sclerosis Care Liaison:** The MS Care Liaison serves as a point of contact for Veterans with MS at the MS Support Program. They are knowledgeable about MS and able to refer Veterans to local providers and resources appropriate for their needs, set up telehealth care as appropriate with the MS Regional Program, or refer to the MS Regional Program if the home facility does not have the required services.

2. NATIONAL SYSTEM OF MS CARE

The national system of MS care consists of the MSCoE East and West Coordinating Centers, at least one MS Regional Program in each VISN, and MS Support Programs in the other VA medical facilities. In VISNs with large geographic areas or large numbers of Veterans with MS, more than one MS Regional Program may be designated. Veterans with MS within each VISN are identified through MSCoE databases. The Director of each MS Regional Program works with MSCoE and the MS Support Programs to determine the location of Veterans with MS within their catchment area. Veterans with MS may be seen in MS Regional Programs, MS Support Programs, or non-VA facilities as needed for MS specialty care evaluations. MS Regional Programs and MS Support Programs should coordinate with non-VA care providers for Veterans using this option (within VA or with other health insurance programs).

3. POPULATION SERVED

The national system of MS care serves all Veterans receiving care within the VA health care system who have a diagnosis of MS and MS related condition (e.g., clinically isolated syndrome or neuromyelitis optica), or have suspected 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 education and outreach program managed by the MScOE network.

4. MS REGIONAL AND SUPPORT PROGRAMS

A. **MS Regional Program:** MS Regional Program sites can be located at any VA facility responsible for the care of more than 100 Veterans with MS that offers the spectrum of outpatient, inpatient, and specialty care services needed by Veterans with MS. (Facilities that are able to provide the full spectrum of care are often designated as a level 1 facility (i.e. 1A, 1B, or 1C) according to the VA Facility Complexity Model.) The MS Regional Program will endeavor to provide access to all FDA-approved MS disease modifying therapies. 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.

a) **MS Regional Program Staff.**

1) **Director:** The position of MS Regional Program Director is to be filled by a physician or doctoral level nurse practitioner who may serve the given VA medical facility through a part-time or full-time appointment consistent with VHA 1065.01 Productivity and Staffing Guidelines for Specialty Provider Group Practice. The following background requirements are to be met:

- The candidate must meet all existing VA requirements, including credentialing and privileging.
- The candidate should have training or experience in MS management. MS fellowship or related specialty training is encouraged.
- A faculty appointment at the university affiliate is strongly encouraged.

2) **Coordinator:** The MS Regional Program Coordinator (this will usually be a nurse, physician assistant, or nurse practitioner) will provide case management, assist with MS treatment, and provide education to Veterans, caregivers, and other staff. The expanded role of physician assistants and nurse practitioners in the diagnosis and prescribing of medications can be helpful,

3) **Social Worker:** Social workers are assigned to serve the comprehensive social work needs of Veterans with MS referred to the MS Regional Program;

4) **Administrator:** An administrator is assigned to manage administrative assignments of the MS Regional Program;

- 5) **Rehabilitation Therapists:** Access to occupational therapists, and physical therapists or kinesiotherapists with knowledge of MS serving inpatients and outpatients;
 - 6) **Other:** MS Regional Programs should have access to the multidisciplinary team members specified above, and other health professionals including psychologists, pharmacists, dietitians, respiratory therapists, driver rehabilitation specialists, orthopedic surgeons, ophthalmologists, obstetricians, gynecologists, orthotists, and chaplains, as well as Palliative Care, Pulmonary Medicine, and Sleep Medicine programs. A designated pharmacist for MS therapy management is strongly advised.
- b) **MS Regional Program Outpatient Services.** Outpatient clinics provide the full spectrum of MS health care to the local MS population.
- 1) MS Regional Programs should provide an outpatient program of scheduled hours to evaluate and treat Veterans with MS. This should include an infusion center and the capacity for unscheduled visits for Veterans with acute conditions related to MS.
 - 2) The scope of outpatient treatment at the MS Regional Programs should be comprehensive and multidisciplinary. Services provided to an individual are a part of continuum of care and should integrate inpatient and home care when needed.
- c) **MS Regional Program Inpatient Services.** MS Regional Programs are to provide inpatient admissions to a VA medical facility when appropriate. Inpatient admission needs to be considered for severe relapses, infections, or other serious illnesses related to MS. Inpatient services could include rehabilitation, spinal cord injury/disorders, acute and sub-acute medical and surgical care, mental health care, respite care, palliative care, and long-term care.
- B. **MS Support Programs:** Medical facilities caring for Veterans with MS that are not designated as an MS Regional Program, are recommended to have an MS Support Program as outlined below.
- a) **MS Care Liaison.** The Chief of Staff at each VA medical facility without a MS Regional Program is encouraged to designate a staff member within the clinical services as the MS Care Liaison. The MSCoE will provide training for MS Care Liaisons upon request. The individual is to have, or be willing to acquire, appropriate knowledge regarding:
 - The MS disease process;
 - Psychosocial implications for the individual with MS and their family;
 - Resources for MS treatment and rehabilitation;
 - Resources for appropriate clinical and vocational interventions;
 - Prosthetic services for Veterans with MS;

- VHA directives and benefits affecting Veterans with MS;
- Community resources and services for the disabled;
- Local peer counseling programs or groups; and
- Federal laws or regulations regarding disability.

b) **Appointment of MS Support Program Care Teams.** It is recommended that the VA medical facility Chief of Staff appoint an MS Center Care Team at facilities designated as an MS Support Program. This team should consist of a physician or group of health care providers and the designated MS Care Liaison. The team is to provide specialty care and consultative services to the local eligible Veterans with MS. Specialty MS care not available at the local VA medical facility needs to be performed by the MS Regional Program or through an appropriate community care mechanism.

5. MS SYSTEM OF CARE CONTINUUM

A. **Location of Care:** The location of care is dictated by the needs of the Veteran with MS. Care should take place as close to home as possible and may be delivered in a variety of settings and methods, including telehealth. Regardless of the location, providers of MS care should be made aware of the Veteran's admission into the VA system.

B. **Clinical Services:** Primary care and specialty care will take place based on MS related symptoms and comorbid disease. Care will be collaborative with the Veteran's patient aligned care team (PACT). The following outlines the broad clinical services offered to Veterans with MS within the VA system.

a) **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 neurologist or other provider knowledgeable about MS. 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.*

b) **Primary Care.** Veterans with MS will be assigned a primary care provider (within a PACT) for preventive and general medical care at all VA medical facilities. The primary care provider assumes ongoing responsibility for prevention, health maintenance, and treatment for illness. 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 is to be available to advise or assume care should it be necessary; the use of telehealth can be used to facilitate this communication.

- c) **MS Specialty Care.** An annual assessment through a face-to-face visit, e-consult, or telehealth encounters is recommended for all Veterans with MS. An annual assessment is documented, ideally using the MS Assessment Tool which feeds into the MS Surveillance Registry. More frequent specialty follow-up care may be necessary based upon individual disease management issues. *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.*
- d) **Rehabilitation.** Rehabilitation services are commonly required in MS care. Multiple rehabilitation specialties (i.e., kinesiotherapy, nursing, occupational therapy, physiatry, physical therapy, psychology, recreation therapy, rehabilitation nursing, social work, speech therapy, and vocational rehabilitation) are often necessary to address the associated symptoms, impairments, and disabilities of Veterans with MS. Interdisciplinary, inpatient, outpatient, and telehealth rehabilitation services may be a part of the MS treatment plan.
- e) **VA Spinal Cord Injury and Disorders.** The Spinal Cord Injury and Disorders (SCI/D) Centers is a system of care designed to support, promote, and maintain the health, independence, quality of life, and productivity of individuals with spinal cord injuries and/or disorders throughout their lives.
- f) **Palliative Care.** Palliative care is a holistic approach to managing advanced or distressing MS symptoms. The goal of such care is the relief of symptoms caused by MS rather than modifying the disease course. End-of-life palliative care or hospice care occurs when complications related to MS or complications typical of advanced age present a serious and incurable threat to life. Access to hospice care and bereavement counseling are specified aspects of the VHA medical benefits package.
- g) **Respite Care.** Respite care provides caregivers temporary relief from the responsibilities of caring for individuals with MS. Respite care need not be limited to a long-term care unit, but rather may occur 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 facility. Regulations requiring access, duration, and timing of respite stays can be found in VHA Handbook 1140.02, Respite Care.
- h) **Home Care.** Medical rehabilitation and preventive services determined necessary to sustain the Veteran with MS in the community need to be provided. This may require collaboration between social work services, primary care, and specialty care.
- i) **Long-Term Care.** The VHA system of care is committed to supporting a full continuum of care for Veterans with MS, including long-term care. Telehealth technologies may prevent or delay the progression of chronic conditions. 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 aide 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, and not all services available in all VA health care settings.* It is expected that the Veteran with MS who resides in a long-term care facility will continue to have access to the MSCoE network.

j) **Neuropsychological Evaluation and Treatment.** Cognitive deficits are common impairments in MS, even early in the course of the disease. These impairments are frequently associated with loss of employment and function in the home and alter the quality of life for the Veteran and family. Therefore, cognitive testing should be available for all Veterans with MS as required by their providers for management

k) **Mental Health Care.** Mental health issues in general, especially depression and anxiety, 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 are to have access to the full range of mental health services.

l) **Social Work Services.** Veterans with MS are to 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 Veterans with MS.

m) **Telehealth Services.** Telehealth services improve access and enhance the quality of care provided to Veterans. Telehealth services span the continuum of care.

6. HEALTH MANAGEMENT ISSUES THROUGH THE CONTINUUM OF CARE

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

A. **Early Diagnosis of MS:** The diagnosis of MS needs to be considered as soon as possible after an initial neurological attack for progressive syndrome compatible with demyelinating disease. The work-up needs to follow the 2017 revised McDonald Diagnostic criteria or subsequent update. Confirmation of MS by these same criteria needs to be made in Veterans initially presenting to the VA system who carry an MS diagnosis.

B. **Clinical Evaluations and Documentation:**

a) MS-related clinical evaluations are to be documented in CPRS on an annual basis. The following items should be included in this assessment:

- 1) A comprehensive history and neurological exam documenting core outcomes in the MSAT.
 - 2) Veterans with MS who are appropriate candidates for DMTs are to have access to these agents as early in the disease course as possible. See the VA Pharmacy Benefits Management (PBM) Intranet site for Criteria for Use (CFU) of medications used for the treatment of Veterans with MS, www.pbm.va.gov. The MSCoE Consensus Statement, *Relapse and Disease Management in MS*, as well as other MS management strategies and links for VA services are available on the MSCoE website (www.va.gov/MS).
 - 3) An assessment of MS associated symptoms and disabilities and appropriate multidisciplinary referrals, which may include kinesiotherapy, mental health, occupational therapy, pain management, palliative care, physical therapy, prosthetics, neuropsychology, recreation therapy, rehabilitation psychology, pulmonary medicine, sleep medicine, social work, speech therapy, vocational rehabilitation, as well as community health nursing and home health care.
- b) The MS Assessment Tool (MSAT) is a web-based tool that includes core clinical attributes of MS and feeds into the MS Surveillance Registry (MSSR). Each MS Regional Program is responsible for updating these data on their referral MS population each year. Regional programs will have access to the MSSR for their site and affiliated MS Support Programs to assist with clinical management. National statistics on the VA MS population and assessments for each MS Regional Program will be assessed annually. Core MS variables on the MSAT include the following:
- 1) Demographics;
 - 2) MS diagnosis and initial presentation;
 - 3) MS disease course;
 - 4) MS disability (by the European Database for MS (EDMUS) scale); and
 - 5) MS disease modifying medication history.

C. **Referral Guidelines:** The goal of the MS System of Care is to provide competent and convenient care to all Veterans with MS. For many Veterans, this can be provided by their primary care provider in a local facility such as a Community Based Outpatient Clinic (CBOC). Situations that might require transfer of care, either temporarily (for consultation, including via telehealth or other remote means of care) or permanently, to a MS Regional 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 Veteran with newly diagnosed MS 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 consultation regarding changes in functional status that limit prior activities or family, work, and community participation; and
- g) Management of advanced MS.

7. MS EDUCATION

The goal of MS education is to increase provider and Veteran knowledge, self-efficacy, and access to resources through the continuum of disease. Provider and Veteran education are essential to the delivery of health care, early intervention, and adherence to treatment and rehabilitation. While the median age of a Veteran in the United States is about 60 years of age and most are male, 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 health care providers, Veterans, and their 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 website (www.va.gov/MS) offers current educational materials and resources to both health care professionals, Veterans, and others on MS management, care recommendation, and services unique to VHA. MSCoE leadership and staff are available for on-site training, mentoring, and consultation.

B. **Regional MS Care Coordinator Training:** MS education modules and online educational presentations are available to those unable to attend live meetings and symposia. Coordinators are encouraged to earn continuing education units (or specialty equivalent) related to MS treatment and management.

C. **Training of MS Regional Care Teams:** After two years of experience in MS care, it is recommended that the MS Care Coordinator take the exam for MS Certified Nurses (MSCN) or the MS Specialist Certification (MSCC) for non-registered nurse coordinators. *NOTE: For more information about MS nursing care, go to the International Organization for MS Nurses website (www.iomsn.org). For more information about the certification exam, go to the Professional Testing Corporation website (www.ptcny.com).*

8. RESEARCH

The MSCoE coordinate a national research program designed to support VA leadership and improve the care of Veterans with MS. The MSCoE will use VA data sources to assess the needs of Veterans with MS, reporting to VA leadership on an ongoing basis. The MSCoE will coordinate multicenter research into the causes of and treatments for MS and its related symptoms, assisting in the acquisition of VA data for collaborating researchers, clinicians, and administrators. The MSCoE will disseminate

research results to network members through presentations, abstracts, presentations, posters, and the MScCoE website (www.va.gov/MS).

9. REFERENCES

- A. Multiple Sclerosis System of Care VHA Directive 1011.06.
- B. Title 38 U.S.C. 7330, Multiple Sclerosis Centers of Excellence.
- C. VHA Directive 1215, Standards for Veterans Health Administration Centers of Excellence.
- D. Government Accountability Office (GAO) (2016). *Centers of Excellence: DOD and VA Need Better Documentation of Oversight Procedures* (GAO Publication No. 16-54). Washington, DC: U.S. Government Printing Office (GPO).
- E. VHA 1065.01 Productivity and Staffing Guidelines for Specialty Provider Group Practice.
- F. VHA Handbook 1140.02, Respite Care.
- G. 2017 revised McDonald criteria for the diagnosis of MS.
- H. MScCoE Consensus Statement: Relapse and Disease Management in MS.
- I. European Database for MS (EDMUS) scale.