

PARKINSON'S DISEASE SYSTEM OF CARE

1. REASON FOR ISSUE: This Veterans Health Administration (VHA) directive establishes policy and procedures for health care services provided to Veterans with Parkinson's disease (PD) and related disorders. It describes the essential components and procedures of the Parkinson's Disease Research, Education, and Clinical Centers (PADRECCs) centers of excellence that are to be implemented nationally to ensure that all eligible Veterans have access to specialized care for PD and related disorders.

2. SUMMARY OF CONTENTS: This is a new VHA directive that establishes policies and procedures for health care services provided to Veterans with PD and related disorders. It states responsibilities, explains where to find expert opinion on clinical practices, and defines the interaction of facilities, Consortium Centers, PADRECCs, and the National VA Parkinson's Disease Consortium.

3. RELATED ISSUES: None.

4. RESPONSIBLE OFFICE: The Office of Specialty Care Services (10P11) is responsible for the content of this directive. Questions may be referred to the National Program Director of Neurology at 202-461-7120.

5. RESCISSION: None.

6. RECERTIFICATION: This VHA directive is scheduled for recertification on or before the last working day of January 2024. This VHA directive will continue to serve as a national VHA policy until it is recertified or rescinded.

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Acting Deputy Under Secretary for Health
for Policy and Services

NOTE: *All references herein to VA and VHA documents incorporate by reference subsequent VA and VHA documents on the same or similar subject matter.*

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PARKINSON'S DISEASE SYSTEM OF CARE

1. PURPOSE

This Veterans Health Administration (VHA) directive establishes policy and procedures for health care services provided to Veterans with Parkinson's disease (PD) and related disorders. This directive describes the essential components of the PD system of care that must be implemented nationally to ensure that all eligible Veterans have access to PD care. **AUTHORITY:** Title 38 United States Code (U.S.C.) 1710, 7301(b), 7329; Title 38 Code of Federal Regulations (CFR) 3.309.

2. BACKGROUND

a. Parkinson's disease is a progressive neurological disease with no known cure. Approximately 110,000 Veterans currently carry the diagnosis of PD. PD is presumed to be service-connected when a Veteran has been exposed to certain herbicide agents and to contaminants in the water supply at Camp Lejeune, and as a secondary service connection to Traumatic Brain Injury (TBI).

b. The progressive nature and variable symptoms of PD require a multidisciplinary approach to the care of Veterans with PD. The multidisciplinary team consists of neurologists, neurosurgeons, psychiatrists, physiatrists, psychologists, nurses, social workers, rehabilitation therapists (speech, physical, occupational), pharmacists, chaplains, and other allied health professionals who care for Veterans with PD along with their primary care physicians. This multidisciplinary team may be entirely located at a facility or accessed through the PD system of care.

c. There are six Parkinson's Disease Research, Education, and Clinical Centers (PADRECCs). They are: Philadelphia, Richmond, Houston, West Los Angeles, San Francisco, and Portland/Seattle VA medical facilities. These six sites were made permanent PADRECCs by the Veterans Benefits Health Care and Information Act of 2006. **NOTE:** For additional information, see <https://www.parkinsons.va.gov/care.asp>.

3. DEFINITIONS

a. **Parkinson's Disease and Related Disorders.** PD is a progressive disease of the nervous system marked by some combination of tremor, muscular rigidity, loss of balance, and slow, imprecise movement. Other clinical features such as non-motor symptoms including cognition, mood, and sleep issues may also be present. Determining diagnosis of PD versus 'related disorders' (secondary PD, drug induced PD, vascular PD, progressive supranuclear palsy, multi-systems atrophy, dementia with Lewy body) is based on recent diagnosis criteria for PD published by the Movement Disorders Society. **NOTE:** Please see <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.26424> for more information.

b. **Parkinson's Disease Program and Clinical Guide.** The PD Program and Clinical Guide is a document developed by the PADRECCs to inform clinicians of treatment options for Veterans with PD. This document does not prescribe mandatory

clinical practices, but provides expert opinion on best clinical practices. The document also outlines specific details on the structure, function, and interaction of the PADRECCs and the National VA Parkinson's Disease Consortium. **NOTE:** To review this guide, please refer to <https://www.parkinsons.va.gov/clinicians.asp>.

c. **National VA Parkinson's Disease Consortium.** The National VA Parkinson's Disease Consortium is a network of clinicians caring for Veterans with PD and related disorders. **NOTE:** For additional information, see <https://www.parkinsons.va.gov/clinicians.asp>.

4. POLICY

It is VHA policy to ensure that all eligible Veterans with PD and related disorders receive high-quality, subspecialty care that is managed, as clinically indicated, by a facility, Consortium Center, or PADRECC. **NOTE:** This policy does not include a detailed description of all the processes required to provide comprehensive PD care or care across the continuum of PD severity which is covered in PADRECC's separate PD Program and Clinical Guide available at: <https://www.parkinsons.va.gov/clinicians.asp>.

5. RESPONSIBILITIES

a. **Under Secretary for Health.** The Under Secretary for Health is responsible for ensuring VHA compliance with this directive.

b. **Deputy Under Secretary for Health for Operations and Management.** The Deputy Under Secretary for Health for Operations and Management is responsible for:

(1) Communicating the contents of this directive to each of the Veterans Integrated Services Networks (VISN);

(2) Ensuring that each VISN Director has sufficient resources to fulfill the terms of this directive in all PADRECCs or Consortium Centers within that VISN; and

(3) Providing oversight of VISNs to ensure compliance with this directive, relevant standards, and applicable regulations.

c. **Assistant Deputy Under Secretary for Health for Clinical Operations.** The Assistant Deputy Under Secretary for Health for Clinical Operations is responsible for collaborating with the National Director of Neurology Services and the PADRECC Directors in making recommendations regarding PD care and coordination.

d. **Chief Officer, Specialty Care Services.** The Chief Officer, Specialty Care Services is responsible for:

(1) Ensuring the development and maintenance of policy and procedures for the PD system of care.

(2) Collaborating with the National Director of Neurology Services and the PADRECC Directors to make recommendations to the Assistant Deputy Under Secretary for Health for Clinical Operations regarding PD care and coordination.

e. **National Director of Neurology Services.** The National Director of Neurology Services is responsible for:

(1) Developing and maintaining policy and procedures for the PD system of care.

(2) In collaboration with the Chief Officer, Specialty Care Services, working with the PADRECC Directors to ensure compliance with this directive.

(3) In collaboration with the Chief Officer, Specialty Care Services, providing oversight of the PADRECCs that aligns with the requirements outlined in VHA Directive 1215, Standards for Veterans Health Administration Centers for Excellence, dated February 14, 2017.

(4) Reviewing and evaluating recommendations from the Assistant Deputy Under Secretary for Health for Clinical Operations; Chief Officer, Specialty Care Services; and the PADRECC Directors for feasibility and process implementation.

(5) Serving as a subject matter expert to VISN leadership and VA medical facilities to provide guidance on local and regional issues that may affect compliance with this directive.

f. **Parkinson's Disease Research, Education, and Clinical Care Director.** The PADRECC Director is responsible for:

(1) Supporting the National Director of Neurology Services and the Chief Officer for Specialty Care Services in developing and maintaining policy and procedures for the PD system of care.

(2) Complying with the oversight plan provided by the National Director of Neurology Services.

(3) Identifying advances and gaps in PD care and making recommendations for remediation to appropriate VHA Central Office program offices.

(4) In collaboration with the National Director of Neurology Services and the Office of Specialty Care Services, making recommendations to the Assistant Deputy Under Secretary for Health for Clinical Operations regarding PD care and coordination, as well as providing expertise and education for providers, Veterans, and caregivers.

(5) Promoting patient-centered, informatics-based approaches to PD specialist access including telehealth, e-consults, and other e-connected modalities.

(6) Designating Consortium Centers (see Appendix B).

g. **Veteran Integrated Services Network Director.** The VISN Director is responsible for:

(1) Allocating adequate resources to PADRECC and Consortium Centers within the VISN to ensure eligible veterans receiving their care through the VA have access to high-quality PD subspecialty care.

(2) Ensuring that PD care is delivered by qualified, competent staff.

h. **VA Medical Facility Director.** The VA medical facility Director is responsible for:

(1) Ensuring facility staff providing care to Veterans with PD and related disorders, or suspected of having PD, utilize appropriate referral procedures and services as outlined in the PD Program and Clinical Guide at <https://www.parkinsons.va.gov/clinicians.asp>.

(2) For facilities designated as a PADRECC, the VA medical facility Director is responsible for:

(a) Providing adequate space and staffing as outlined in Appendix A.

(b) Complying with further responsibilities provided in the PADRECC Memorandum of Understanding (MOU) agreement. **NOTE:** *The PADRECC MOU details agreements between VA medical facilities and the PADRECC program, approved by VISN and VHA Specialty Care Services.*

(3) For facilities designated as a Consortium Center, the VA medical facility Director is responsible for:

(a) Supporting the Consortium Center Director to the highest extent possible.

(b) Ensuring communication between the Consortium Center Director and the National PD Consortium and PADRECC of any changes in clinic personnel or support that may affect the VA medical facility's designation as a Consortium Center.

NOTE: *For detailed information on the designation and scope of Consortium Centers refer to the PD Program and Clinical Guide at <https://www.parkinsons.va.gov/clinicians.asp>.*

i. **Consortium Center Directors.** The Consortium Center Director is responsible for:

(1) Actively engaging with National PD Consortium activities and maintaining communication with their regional PADRECC regarding education and best practices.

(2) Maintaining active movement disorders clinical practice, and referring patients to regional PADRECCs, if needed.

(3) Communicating with National PD Consortium and PADRECC if they will no longer serve as a Consortium Director or the Consortium Center needs to close.

6. NATIONAL SYSTEM OF CARE

The goal of the National System of Care is to provide appropriate care, in the appropriate location, time, and capacity as dictated by the natural progression of disease. This not only includes access to state-of-the-art diagnostic and treatment modalities through the course of the disease, but also access to prosthetics, pharmacy services, social work services, spiritual care services and multidisciplinary care involving access to speech therapy, occupational therapy, physical therapy, and other physician specialists to care for the specific needs of Parkinson's disease and movement disorder patients in an integrated fashion. Find detailed description in the PD Program and Clinical Guide at <https://www.parkinsons.va.gov/clinicians.asp>.

a. **National VA Parkinson's Disease Consortium.** All VA health care providers who serve Veterans with Parkinson's disease and movement disorders (regardless of capacity) are invited and encouraged to register as a member of the Consortium. Membership grants access to a variety of PD resources. **NOTE:** *For additional information, please refer to <https://www.parkinsons.va.gov/Consortium/MembershipandConsortiumCenterDesignationForm.asp>.*

b. **Hub and Spoke Model of Care.** Given the size of the population of Veterans with PD and related disorders seeking treatment in VA and their distribution across the country, it is feasible to provide access to high quality subspecialty care through a hub and spoke network of six regional PADRECCs and at least one designated Consortium Center at each VISN.

(1) Consortium Centers are PADRECC-designated VA movement disorder clinics that serve as a local source for PD specialty consultation and education; and extend the reach of specialty care for PD and related disorders to Veterans who cannot travel to a PADRECC.

(2) Veterans with PD and related disorders may be referred to one of the PADRECCs, Consortium Centers, or non-VA facilities as needed for PD specialty care evaluations. Please see the PD Program and Clinical Guide at <https://www.parkinsons.va.gov/clinicians.asp> for more information on referrals.

(3) Primary care and, in some cases, non-PD specialty care (e.g., physical therapy, speech therapy) is provided at locally accessible VA facilities within specified referral areas and at non-VA facilities.

7. POPULATION SERVED

The National System of Care serves all Veterans receiving care within the VA health care system with a diagnosis of PD and related disorders, those with suspected PD, and those being evaluated for a diagnosis of PD and related disorders. In addition, Veterans, family members, caregivers, health care providers, and administrative staff who seek information about PD and related disorders are included in the target population served by The National System of Care.

8. EDUCATION AND TRAINING

The PADRECCs will provide educational programs designed to increase clinician, Veteran, and caregiver knowledge about the disease process, its management, and resources available through the VA system. Refer to: <http://www.parkinsons.va.gov/> for a list of provider and Veteran education programs and tools.

a. **Provider Training.** The PADRECCs will provide education and training for VA clinicians and allied health professionals to increase knowledge of PD management and VA specific issues relevant to the care of PD and related disorders. Through the Office of Academic Affiliations, the PADRECCs have established a two-year fellowship program in PD and related disorders.

b. **Veteran and Caregiver Education.** The PADRECC's education program covers all aspects of PD care and management and is delivered using a wide range of mediums (including but not limited to Web-based, newsletters, written documents, teleconferences and face-to-face meetings). The programs and support groups are designed for Veterans with PD and caregivers to increase knowledge and facilitate greater participation in care.

9. RESEARCH

The PADRECCs will have a diverse research program to advance investigations into the epidemiology, treatment, prevention, and basic pathophysiology of PD and related disorders. The PADRECCs will also coordinate multi-center research into the causes of and treatments for PD and related disorders.

10. RECORDS MANAGEMENT

All records, regardless of format (paper, electronic, electronic systems), created in this directive shall be managed per the National Archives and Records Administration (NARA) approved records schedules found in VHA Records Control Schedule (RCS) 10-1. If you have any questions regarding any aspect of records management you should contact your facility Records Manager or your Records Liaison. See also VHA Directive 6300, Records Management, dated October 22, 2018.

11. REFERENCES

- a. 38 U.S.C. 7329.

b. VHA Directive 1215, Standards for Veterans Health Administration Centers of Excellence, dated February 14, 2017.

c. VHA Directive 6300, Records Management, dated October 22, 2018.

d. VHA Handbook 1065.01, Productivity and Staffing Guidance for Specialty Provider Group Practice, dated May 4, 2015.

e. Postuma, R., et al. MDS clinical diagnostic criteria for Parkinson's disease. *Movement Disorders*, Volume 30, Issue 12, October 2015. Pages 1591-1601. <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.26424>.

**PARKINSON'S DISEASE RESEARCH, EDUCATION, AND CLINICAL CENTERS
(PADRECCs)**

a. **Scope of Services.** The goal of the PADRECC services is to improve quality of life by providing comprehensive medical and surgical care to Veteran patients with Parkinson's disease (PD) and related disorders, advancing investigation into the cause and cure for PD and related disorders, and enhancing understanding of these disorders through education and research. The PADRECCs provide services that address the unique demands of delivering subspecialty health care services to individuals with PD and related disorders as outlined in the PD Program and Clinical Guide at <https://www.parkinsons.va.gov/clinicians.asp>.

b. Program staff may include:

(1) **Director.** The Director is to be filled by a physician who may serve the given VA medical facility through a part-time or full-time appointment ranging from .625 to 1.0 full-time employee equivalent (FTEE), and consistent with VHA Handbook 1065.01, Productivity and Staffing Guidance for Specialty Provider Group Practice, dated May 4, 2015. This person must have experience in the diagnosis and management of PD and related disorders, and the following background requirements must be met:

(a) Completion of a fellowship in movement disorders;

(b) At least 5 years' experience in PD and related disorder diagnosis and management; and

(c) Experience in movement disorder research and teaching.

(2) **Associate Clinical Director.** The Associate Clinical Director is to be filled by a physician who may serve the given VA medical facility through a part-time or full-time appointment ranging from .625 to 1.0 FTEE, and consistent with VHA Handbook 1065.01. This person will have experience in the diagnosis and management of PD and related disorders.

(3) **Neurosurgeon.** The neurosurgeon may serve the given medical facility through a part-time appointment of at least .375 FTEE, and consistent with VHA Handbook 1065.01. This person will have experience with movement disorders surgeries.

(4) **Associate Director for Research.** The Associate Director for Research is to be filled by an individual with demonstrated competence in research administration and hold a regular faculty appointment in an academic department of the affiliated medical school or appropriate professional school in a university. The VA appointment should range from 0.625 FTEE to 1.0 FTEE.

(5) **Associate Director for Education.** The Associate Director for Education is to be filled by an individual with demonstrated competence in developing and implementing education and training programs for professionals, Veterans and their caregivers. The VA appointment should range from 0.625 to 1.0 FTEE.

(6) **Clinical Nurse Coordinator.** The Clinical Nurse Coordinator will provide coordination of follow-up activities associated with patient care and provide education to Veterans, caregivers, and other staff. The VA appointment should be 1.0 FTEE.

(7) **Administrative Officer.** An administrative officer is necessary to manage all administrative assignments of the PADRECC. The VA appointment should be to 1.0 FTEE.

(8) **Medical Support Assistant.** A medical support assistant is necessary to manage consults, schedule patients, and clinic coordination. The VA appointment should be 1.0 FTEE.

c. **Specialties.** The following specialties must be provided by the facilities to support the PADRECC clinical mission of optimum care:

(1) Social Work;

(2) Rehabilitation Therapy such as physical therapists, speech therapists/pathologists, and occupational therapists with knowledge of PD and related disorders serving inpatients and outpatients;

(3) Behavioral Health;

(4) Neuroradiology;

(5) Anesthesia;

(6) Surgical theaters and support staff (nursing);

(7) Pharmacist;

(8) Nutritionist;

(9) Palliative care specialist; and

(10) Chaplain.

d. **Outpatient Services.** The PADRECC's outpatient clinics provide the full spectrum of PD health care to the local Veteran PD population.

(1) The PADRECCs must provide an outpatient program of scheduled hours and treatment, including the ability to accommodate unscheduled visits for Veterans with acute conditions related to PD and related disorders.

(2) The scope of outpatient treatment at the PADRECCs must 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.

e. **PADRECC Inpatient Services.** The PADRECCs provide the full spectrum of PD health care, coordination, and participation in inpatient admissions at their local VA medical facility, as appropriate. Inpatient services provided by PADRECCs could include consultation services for acute and sub-acute medical and surgical care, post-surgical management, respite care, palliative care, and long-term care.

f. **PADRECC Quality Assurance.** Each PADRECC is to undertake service-level quality improvement activities for its service area that monitor critical aspects of care and provide an on-going and continuous evaluation of the program to address patient outcomes.

CONSORTIUM CENTERS

The Consortium Centers exist to improve access to specialty care for all Veterans with Parkinson's disease (PD) and related disorders. VA medical facility Directors caring for Veterans with PD who have a Consortium Center are encouraged to support the Center to the highest extent possible.

a. **Designation of Consortium Centers.** VA movement disorders specialists or general neurology clinicians with expertise or interest in the field of movement disorders can apply for designation of their VA medical facility as a Consortium Center through the Consortium Coordinating Office (operated at the Philadelphia PADRECC). Prior approval and support of the local VA medical facility administration is necessary. Designation is determined by the level of skill and interest of the requesting staff as well as geographic need. A Consortium Center Director is named at each approved site to oversee clinic operations and maintain regular contact with their regional PADRECC and the Consortium Coordinating Office.

b. **Scope of Services at Consortium Centers.** Consortium Centers offer specialty clinics for Veterans with PD and related disorders in a regional capacity as outlined in the PD Program and Clinical Guide at <https://www.parkinsons.va.gov/clinicians.asp>.

c. **Veteran Referral to a Consortium Center.** When a Veteran with PD or related disorders cannot access direct care at a PADRECC facility, the VA primary care provider or general neurologist is encouraged to refer the patient to a local Consortium Center, as outlined in the PD Program and Clinical Guide at <https://www.parkinsons.va.gov/clinicians.asp>.