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1. PURPOSE
This program guide describes the essential components and procedures of the Parkinson’s disease (PD) program that are to be implemented nationally to ensure that all enrolled Veterans, wherever they live, have access to PD care. This program guide is an addendum to VHA Directive 1420 Parkinson’s Disease System of Care.

2. BACKGROUND
In 2001, the Department of Veterans Affairs (VA) established the Parkinson’s Disease Research, Education and Clinical Centers (PADRECCs) to care for the approximately 80,000 (this number has grown to 110,000) Veterans afflicted by Parkinson disease. The six Centers of Excellence were founded at the Philadelphia, Richmond, Houston, West Los Angeles, San Francisco, and the Portland/Seattle VA Medical Centers. Each PADRECC is designed to deliver state-of-the-art clinical care, research, and educational programs to an expansive geographic region or “service area” (see Figure 1). These Centers are staffed by movement disorders specialists and researchers. The PADRECCs were made permanent by H.R.6342, Section 7329, Veterans Benefits, Health Care and Information Act of 2006.

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. To accomplish this the PADRECCs established the National VA Parkinson’s Disease Network (NVAPDN). This network consists of at least seven PADRECCs (hubs), at least one designated Regional Parkinson’s and Movement Disorders Center (RPMDC) in each VISN and PADRECC Associated Sites (PAS) (spokes) dispersed throughout the United States. These RPMDCs and PASs offer Veterans convenient access to specialized movement disorders services within all Veterans Integrated Service Networks (VISNs). The PADRECCs and NVAPDN create a hub and spoke model of care that is highly innovative and effective.

Parkinson’s Disease Research, Education & Clinical Center (PADRECC) Directors: The PADRECC Directors serve as subject matter experts to the Neurology National Program Executive Director (NPED) on issues that affect health care of Veterans with PD, including but not limited to identifying advances in PD care, gaps in care and providing expertise and education to providers, Veterans, and caregivers. The Directors support the National PADRECC Director in promoting patient-centered, informatics-based approaches to PD specialist access including telehealth, e-consults, and other e-connected modalities. They collaborate with VISN Directors to ensure that all RPMDCs in their PADRECC catchment area have consultation access to that PADRECC (e.g., an active inter-facility consult process). The Directors collaborate with VISN Directors, Medical Center Directors and Chiefs of Staff in designating RPMDCs or PASs.
3. DEFINITIONS

A. PADRECC
The PADRECC is a multidisciplinary group of health care providers who provide primary and specialty services for Veterans with PD and related disorders. Specialty services include chemodenervation therapy, DBS stimulation adjustments and surgical treatment options for movement disorders. In addition to clinical care, the PADRECCs must also have educational and research components to their programs. The PADRECCs were chosen by a peer review committee and established by law (H.R.6342, Section 7329, Veterans Benefits, Health Care and Information Act of 2006). The PADRECC Director must be at least mid-career movement disorders trained neurologist.

B. RPMDC
The RPMDC is a group of healthcare providers offering multidisciplinary care to Veterans with PD and related disorders. They provide primary and specialty services, including chemodenervation therapy and DBS stimulation adjustments. RPMDCs are designated by the VISN Director, in collaboration with the Neurology NPEd and National PADRECC Director. The RPMDC Director must be a neurologist with specialty fellowship or substantial experience in the management of patients with movement disorders.

C. PAS
PAS sites provide specialized care for Veterans with PD and related disorders. The PAS Director must be a neurologist with interest in treating Veterans with movement disorders.

D. Parkinson’s disease PD is the second most common neurodegenerative disorder. It was first described in 1817 by Dr. James Parkinson in An Essay on the Shaking Palsy.

E. Epidemiology
PD has an estimated prevalence of around 200/100,000 with some studies quoting up to 329/100,000. The number of people living with the disease in the US is up to one million and worldwide more than five million. The likelihood of developing Parkinson’s disease increases with age. It typically begins in the age range of 50-60 years with the average age of onset 62.4 years. Onset before age 30 is rare but up to 10% of cases begin by age 40. Some studies suggest that men have a slightly higher risk of developing PD.

F. Etiology
The cause of Parkinson’s disease remains unknown. There is a loss of dopaminergic neurons in the substantia nigra as well as other dopaminergic and non-dopaminergic areas of the brain. Research indicates that there are genetic and environmental factors that contribute to the development of PD.
G. Diagnosis
The diagnosis of PD is largely clinical, requiring careful integration of the history and physical examination. Response to dopaminergic medication is also useful in the diagnosis. Early in the disease, up to 5-10% of patients with PD are misdiagnosed. Up to 20% of patients diagnosed with PD have other diagnosis at autopsy such as the atypical Parkinson syndromes, Alzheimer disease, or cerebrovascular disease. Diagnostic criteria such as the United Kingdom (UK) Brain Bank Criteria have been proposed, which increase the accuracy of diagnosis to 90%. The accuracy of diagnosis increases significantly when the examination is performed by specialists with movement disorders training.

H. Symptoms
PD is characterized by the classic motor symptoms of bradykinesia, rigidity, and rest tremor. Non-motor symptoms are increasingly highlighted as a major cause of disability and poor quality of life. These symptoms include cognitive and sleep dysfunction, depression, constipation, hyposmia, speech and swallowing dysfunction, and orthostatic hypotension.

I. Clinical Course
PD is a chronic neurodegenerative disease with a slow progression of symptoms over years; however, the course is highly variable. Early in the disease, patients present with symptoms of stiffness, slowness, or tremor. Later, patients develop postural instability. Over time, dyskinesias and motor fluctuations often develop. As the disease progresses, cognitive dysfunction and non-motor symptoms can become a major issue.

J. Disease Modifying Therapies (DMTs)
At the present time, the medications that we offer patients are symptomatic only and are not neuroprotective. The potential for a medication to have a disease modifying effect is an area of active study.

K. Hub and Spoke Care Model
In addition to the six PADRECCs, each VISN will have at least one RPMDC and/or PAS that will serve as a local source for PD specialty consultation and education. The primary care for individuals with PD will occur at their local VA medical facility.

4. SCOPE
The mission of the PADRECC is to support quality of life by providing comprehensive medical and surgical care to Veteran patients with Parkinson’s disease and other movement disorders, advancing investigation into the cause and cure for Parkinson’s disease, and enhancing understanding of the disorder through education and research. PD is a unique disease due to its presentation with both disabling motor and non-motor symptoms that can affect areas ranging from mood, sleep to swallowing and falls. The diagnosis of this disease is also different than many neurological diseases given it is a clinical diagnosis, requiring the skill of an expert movement disorders physician to confirm and treat. Due to an evolving symptom profile, Parkinson’s disease requires close follow-up and adjustment of the treatment plan of the PD patient. Additionally, the
medications used in PD add a unique profile of other issues to be considered, including dyskinesias, impulse control disorders, hallucinations, and hypotension. Medication administration requires a high level of compliance and complex schedules and regimens and is a unique and crucial part of the treatment plan in Parkinson’s disease.

This guide defines services that can be provided at VA medical facilities. It is not the purpose of this Guide to describe all aspects of PD treatment and programming that could be appropriate and effective. VISNs and facilities are encouraged to engage in clinical consultation and educational opportunities with the PADRECC to advance services for their local Veterans.

The PADRECC 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 PD care (refer to: http://www.parkinsons.va.gov/).

5. PD SYSTEM OF CARE CONTINUUM
A. PD Specialty Care
The goal of the VHA system of care is to provide Veterans with Parkinson’s disease and movement disorders 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 social work services, spiritual care services and interdisciplinary care involving access to speech therapy, occupational therapy, physical therapy, and other physician specialist to care for the specific needs of Parkinson’s disease and movement disorder patients in an integrated fashion.

B. Telehealth Services
Telehealth is defined as providing the right care in the right place at the right time through the effective and appropriate use of health information and telecommunications technology. PADRECCs provide various telehealth services to improve access and enhance the quality of care provided to patients.
1. Effective Telehealth services include:
   a. New patient consultation
   b. Routine follow-up care
   c. Deep Brain Stimulation adjustments
2. Telehealth services are provided by utilizing VA Video Connect to other VA facilities (both inside and out of PADRECC VISN), CBOCs (Community Based Outpatient Clinics), some VA State Nursing Homes, into the patient’s home, or anywhere the patient is located. To arrange services please contact your local medical center’s Facility Telehealth Coordinator.

C. Emergency Care
Emergency services vary from center to center, however each PADRECC has a neurologist on site that may assist the Emergency Department physician in the care of the Parkinson’s patient as necessary. This is often relevant in emergencies, even when
not related to PD, as many questions arise about medication management during hospitalization.

D. Primary Care
Each PADRECC has a movement disorders specialist on site that may assist the Primary Care physician in the care of the Parkinson's patient as necessary. Further, Parkinson’s patients cared for within the PADRECC network benefit from having frequent communication between primary care providers (PCPs) and PD specialists. Because PD affects many systems of the body, changes to medications, such as blood pressure medications, often require input from both the PCP and the PD specialist to ensure that these changes don’t result in fainting.

E. Rehabilitation
Patients with PD often have significant rehabilitation needs. Access to a physical therapist with specialty training in Neurology is very important to the care of PD patients. This is important for maintenance of balance and prevention of falls, by providing walkers and other assistive devices at the appropriate stage of disease progression. Further, there is evidence that exercise may improve how patients experience their disease and should be emphasized. Speech and swallowing evaluations and therapies are imperative. The most common cause of death in Parkinson’s is aspiration pneumonia, and thus speech therapy is very important for assessing how patients handle food and secretions.

F. Palliative Care
Although there are many treatments to help with the symptoms of PD, the disease is progressive and almost all patients eventually arrive at a stage of disease where “symptom management” becomes paramount. Palliative care demonstrates compassion, commitment, and hopefulness that suffering can be relieved. Palliative care services may include a team whose focus is on the needs of the patient as they lose independence and often develop concerns about being a burden on their families and loved ones. Palliative care specialists in the VHA should communicate with providers, patients, and families to determine the goals of care, wishes for advanced directives, which include resuscitation status and the use of potentially life-prolonging care, as well as ensuring that the patient’s family is not suffering from caregiver burden.

1. When to Refer for Palliative Care
The following signals a need to relieve suffering and address the patient’s well-being by use of palliative care specialists:
   a. Physical deterioration evidenced by regular falls and/or markedly limited mobility (i.e. bed-bound)
   b. Onset of clinically significant cognitive disability
   c. Visual hallucinations unrelated to medications
   d. Need for residential care
   e. Lack of medication responsiveness
   f. Overwhelming disability from non-motor symptoms
   g. Pain that is chronic and controlled inadequately
h. Severely reduced quality of life because of illness.
i. Patient and/or family difficulty in making care decisions such as: hospice, peg tube etc.

2. Palliative Care Setting
Patients with Parkinson’s disease can be provided palliative care in multiple settings:

a. Home
b. Outpatient Clinic
c. Long-term-care facility
d. Hospital or intensive care units
e. Palliative care clinics. Several centers have multidisciplinary clinics called “Palliative care clinics” that focus on palliation and a realization that patients may benefit from services such as social work and chaplaincy. These services may happen independently.

G. Respite Care
Respite care provides caregivers temporary relief from the responsibilities of caring for individuals with Parkinson’s disease. Respite care is for Veterans who need help with activities of daily living and for Veterans who are isolated, or their caregiver is experiencing burden. Respite literally means “a period of rest” and is recognized as an important consideration for families and caregivers of physically dependent Veterans.

1. VA offers two types of respite care and both should be scheduled in advance:

a. Home Respite Care: pays a person to come to a Veteran’s home or for a Veteran to go to an adult day health care program while their family caregiver gets a respite.

b. Nursing Home Respite: pays for a Veteran to go to a nursing home while the family gets a respite. Nursing home respite may take place in a VA Community Living Center or a VA contracted community nursing home and is available for a maximum of 30 days each calendar year and should not exceed 14 days in one stay. Any individual who has been hospitalized is not eligible for respite care until 1 month after discharge from an inpatient stay. Veterans may be subject to a copay for respite care depending on service connection status and income. To learn more about VA Respite Care visit LINK: _Respite Care - Geriatrics and Extended Care (va.gov)_

H. Home Care
Medical, rehabilitation, and preventive services determined necessary to sustain the Veteran with PD in the community should be provided. This will require collaboration between Social Work Service (SWS), 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 Parkinson’s disease including long-term care. The goal of long-term care is to assist Veterans with PD 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. Connected Care/Telehealth Services, Home Telehealth (CCHT) monitors patients at home using home telehealth technologies to prevent or delay Veterans needing to leave their home for the management of chronic conditions and to provide non-institutional care. The continuum of extended care services for Veterans with PD is a mix of services designed to meet eligibility requirements, individual needs, family needs, personal preference (choice), and the promotion of independent community living whenever possible. Depending on eligibility options within VHA, include:

1. Care at a designated VA long-term care facility (VA Contracted Nursing Home)
2. VA nursing home care unit-Community Living Center (CLC)
3. Skilled home care services
4. Homemaker or home health aide services
5. Adult Day health care
6. Community-based primary care
7. Community residential care
8. Sub-acute intermediate care
9. Geriatric Evaluation and Management Unit (GEMU)
10. Geriatric Research and Education Clinical Center (GRECC)
11. Assisted living
12. State nursing homes
13. Domiciliary care
14. Respite care
15. Hospice care
16. Medical Foster Homes

NOTE: The preceding list is not all-inclusive and not all services are available in all VA health care settings.

NOTE: Nursing home referrals should 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.

NOTE: It is expected that the Veteran with Parkinson’s disease, who resides in a long-term care facility, will continue to have access to the PADRECC network.

J. Mental Health Care
Mental health issues, particularly anxiety and depression, are common in individuals with Parkinson’s disease and are frequently overshadowed by their physical problems. All providers caring for persons with PD should screen for mental health issues as well as cognitive decline, offer treatment, and make appropriate referrals. Mood disorders should be assessed regularly, including suicide risk assessment. All Veterans with
Parkinson’s disease should have access to mental health and neuropsychological services.

The National Tele-Mental Health Center offers Parkinson’s Disease Neuropsychiatry consultative services for Veteran’s with PD or related disorders (e.g., dementia with Lewy bodies), including but not limited to, those with psychiatric or cognitive symptoms who can benefit from an initial psychiatric evaluation and management recommendations; those with treatment-refractory symptoms that can benefit from a second opinion; or those who would benefit from a baseline, comprehensive psychiatric and limited cognitive evaluation as part of routine clinical care. Please use this LINK: pdn-factsheet.docx (sharepoint.com) for more information.

K. Social Work Services
Veterans with PD should 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 PD 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:
1. Promoting mental, vocational, and social rehabilitation
2. Facilitating the individual’s return to the community at the highest level of functioning possible
3. Advocating for health care services both within and outside of VHA (e.g., VA prosthetic items, Medicare, Medicaid, and Social Security Disability, skilled homecare)
4. Providing care management to Veterans and their caregivers within the VA and the community to ensure continuity of care
5. Providing linkages and referrals to access VA and community supportive services for PD
6. Assisting with alternative living arrangements when necessary
7. Assisting in advance care planning, specifically discussion of Advance Directives and end of life issues
8. Advising patients regarding Veteran’s benefits and compensation programs (e.g., PD service-connection, VA Aid and Attendance funding, and VA Vocational Rehabilitation) and assisting with travel benefits.
9. Providing supportive counseling and education related to new diagnosis and adjustment to a chronic illness
6. POPULATION SERVED
The PADRECCs serve all Veterans with a diagnosis of PD, those with suspected PD, and those being evaluated for a diagnosis of PD and other movement disorders. In addition, Veterans, family members, caregivers, health care providers, and administrative staff who seek information about PD are included in the target population served by the PADRECC.

7. HEALTH MANAGEMENT ISSUES THROUGH THE CONTINUUM OF CARE
Parkinson’s disease has both motor and nonmotor features; therefore, care should be tailored to an individual patient’s needs. The goal of PD management is to slow disease progression, prevent complications, and maximize quality of life.

A. Diagnosis of PD
The diagnosis of PD is largely a clinical one. It requires a detailed history and physical exam of the patient, as well as continued long term follow up. Even in the hands of an expert with movement disorders training and using specific criteria for diagnosis such as the UK Brain Bank criteria, the accuracy of diagnosis of PD may not exceed 90% when post-mortem pathology is used as the gold-standard. There are a number of atypical parkinsonian syndromes that can be misdiagnosed, especially early in the course of PD. Clinical indicators of a Parkinson-plus syndrome instead of PD include poor response to levodopa, early and prominent autonomic dysfunction (such symptomatic postural hypotension, urinary incontinence or retention requiring catheterization, fecal incontinence or persistent erectile dysfunction), lack of tremor, prominent speech or bulbar dysfunction and early falls at or just after onset of symptoms. Lack of asymmetry at onset of the disease and rapid progression (to Hoehn and Yahr stage 3 in 3 years) are also concerning for a Parkinson-plus syndrome. There are also secondary causes of Parkinsonism, such as cerebrovascular disease, normal pressure hydrocephalus, medication-induced Parkinsonism and numerous other toxic/metabolic conditions that can cause Parkinsonism. In addition, Parkinsonism may be the manifestation of a functional neurological disorder.

B. Clinical Evaluations and Documentation
The above symptoms should be carefully screened for, and a general examination performed including mental status and general neurological examination. The motor examination can be conducted with the validated Movement Disorders Society Unified Parkinson Disease Rating Scale (MDS-UPDRS) but it is not mandatory. LINK: https://www.movementdisorders.org/MDS-Files1/PDFs/Rating-Scales/MDS-UPDRS_English_FINAL.pdf
A detailed review of the current and past medication lists should be performed to rule out drug-induced Parkinsonism. If agents such as antipsychotics or antiemetics are being administered to a patient with Parkinsonism, these agents should be tapered off for at least 6 months and clinical reassessment should be performed before the diagnosis of idiopathic Parkinson’s disease can be made. The in-office dopaminergic challenge has remained controversial and is not routinely performed in making the diagnosis of PD. More importance is placed on the response to chronic dopaminergic therapy and progression of the patient’s signs and symptoms to medications over time.
Routine use of other tests such as olfaction testing and neurophysiological testing is not indicated due to low specificity and sensitivity. Routine imaging with magnetic resonance imaging (MRI), sonography, and functional imaging such as positron emission tomography (PET) or single-photon emission computed tomography (SPECT) scans (e.g., DaTSCAN) are also not mandated for all patients. These can be used as supportive measures in diagnostically challenging cases, but do not replace the clinical approach to diagnosis. (see “Clinical Indications for the use of Dopaminergic Functional Imaging (Clinical Indications to use DFI}). MRI of the brain is especially helpful in patients with vascular risk factors or history of neoplasm or atypical presentations to rule out strokes, cancer, normal pressure hydrocephalus, subdural hematomas, or infections. LINK: https://www.parkinsons.va.gov/PARKINSONS/resources/DFI.asp. Documentation of non-motor symptoms such as rapid eye movement (REM) sleep behavior disorder, anosmia, constipation, and depression should also be performed. REM sleep behavior disorder is a largely recognized risk factor for development of Parkinson’s Disease and related disorders such as Lew Body Dementia and Multiple System Atrophy. In addition, anosmia, constipation, and depression are all considered prodromal features and the presence of any combination of these symptoms significantly increases the risk of developing these disorders. A CPRS template has been developed that includes the key historical motor and non-motor questions, UPDRS, the general and focused movement disorders examination. This can be obtained from the PADRECCs and installed with the assistance of the local VA Medical Center Information Resource Management Services.

C. Annual Exam
Every Veteran with a diagnosis of PD needs to have an annual general and neurological examination. This evaluation should include quality care indicators that were developed by the PADRECCs and adopted by the American Academy of Neurology and then updated in 2020. LINK: 2020-parkinson-disease-measurement-set-final.pdf (aan.com)

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

2. The PADRECCs help facilitate the goal of ensuring PD patients in their region are evaluated annually either at the PADRECC site or within other components of the NVAPDN as needed. This is accomplished by continuing education and raising awareness of spoke facility providers, as well as through extended clinical care such as Telemedicine.

3. If an influenza or a pneumococcal vaccination are not offered in primary care, Veterans with PD 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 links below). Veterans with PD should also follow CDC guidelines regarding COVID vaccinations.

https://www.cdc.gov/vaccines/vpd/pneumo/hcp/PCV13-adults.html
https://www.cdc.gov/flu/professionals/acip/2017-18summary.htm
4. The recommended annual neurological evaluation should include:
   a. A comprehensive history and neurological exam documenting laboratory evaluation as clinically appropriate, especially if dementia is present. Lab studies screening for treatable causes of dementia including CBC, TSH, B12, basic metabolic panel, as well as syphilis testing in an at-risk population;
   b. Assessment of medications and reinforcement of compliance should be performed, including a review of specific times that medications are taken. NOTE: Timing of medications should be reviewed with respect to dietary amino acids as well, as dietary protein can impair the absorption of levodopa if taken within 30 minutes of levodopa administration. Pill timers, pill boxes and alarms may also help with compliance.
   c. Screening for mild cognitive impairment, dementia, hallucinations, impulse control disorders, sleep disorders, or bowel, bladder, speech and swallowing dysfunction, as well as fall risks. NOTE: A number of screening tools may assist in the objective measurement of these complaints that are common in PD.

   1. Depression inventories such as the Beck Depression Inventory (BDI), Hamilton Depression Scale or Montgomery-Asberg Depression Rating Scale (MADRS) have been suggested by the American Academy of Neurology (AAN). The Geriatric Depression Scale (GDS- Short) is also used as a screening measure for depression in older adults.
      LINK: http://geriatric toolkit.missouri.edu/cog/GDS_SHORT_FORM.PDF

   2. Mental State. The Montreal Cognitive Assessment (MoCA) is recommended by the PADRECCs. The Mini Mental State Exam (MMSE) and the Cambridge Cognitive Examination have been previously recommended by the AAN.
      LINK: https://www.parkinsons.va.gov/Consortium/MoCA.asp
      LINK: Modified-Mini-Mental-Exam-MMSE.pdf (bmc.org)

   3. Sleep and excess daytime somnolence. The Epworth Sleepiness Scale (ESS) is often used to measure the level of daytime sleepiness. A sleep history is used to detect rapid eye movement sleep behavior disorder (RBD), restless leg syndrome (RLS), and excessive daytime sleepiness.
      LINK: https://www.cdc.gov/niosh/work-hour-training-for-nurses/02/epworth.pdf

   4. Impulse Control Disorders (ICD). ICDs may be detected with a screener such as the Questionnaire Impulsive-Compulsive Disorders in Parkinson’s Disease (QUIP) and followed by a comprehensive clinical interview/history to determine range and severity of symptoms as well as the need for clinical management.
5. Assessment of mobility and safety including driving and fall risk, swallowing, self-care including activities of daily living, vocational, and social support needs.

6. Encouragement of regular exercise, medication compliance, smoking cessation and alcohol moderation, as well as maintenance of general health follow-up/screening.

7. An opportunity for discussion of end-of-life issues provided at least yearly, if appropriate.

8. Multidisciplinary referrals, which may include physical therapy, occupational therapy, speech therapy, psychiatry, psychology, neuropsychology, social work, sleep medicine, geriatrics or primary care clinic, palliative care, and home health care.

D. Treatment of Early Parkinson’s Disease Symptoms

Veterans with PD who are appropriate candidates for medications should have access to these as soon as the need arises. An algorithm for initiating treatment was developed by the PADRECCS and is available online. LINK: https://www.parkinsons.va.gov/Consortium/PocketCard/PocketCard19.pdf

The decision to treat is largely based on the presence of disability, as well as the age and co-existing medical issues of the patient. Additional consideration is given to the potential for possible long-term complications.

NOTE: Refer to VA Pharmacy Benefits Management (PBM) Intranet site for guidance on medications used for the treatment of patients with PD LINK: Pharmacy Benefits Management Services Home (va.gov). This is an internal VA Web site, not available to the public.

1. Federal Drug Administration (FDA)-Approved Medications for PD Motor Symptoms. The medications are listed below.

   a. Levodopa Preparations - Levodopa is most potent compound used in treating the motor features and improving activities of daily living (ADLs) of PD. Carbidopa prevents peripheral conversion of levodopa into dopamine, allowing the former to cross the blood-brain-barrier, and prevents nausea that would likely occur if using levodopa alone.

      1. Levodopa/Carbidopa (Sinemet®) is available in immediate release and controlled release preparations in various dosage strengths; most common of which is 25/100 IR and 25/100 CR and 50/200 CR (CR is also known as SA in the VA system). It is on the VA formulary.

      2. Parcopa® is an orally disintegrating tablet (ODT) containing carbidopa/levodopa. Its advantage is that melting of the tablet on the tongue does not require water for swallowing. It is non-formulary in the VA.

      3. Levodopa/Carbidopa/Entacapone (Stalevo®) is a combined formulation of levodopa/carbidopa with the COMT inhibitor entacapone. It is on the VA formulary.
4. Levodopa/Carbidopa (Rytary®) capsules contain a combination of immediate release and sustained release beads. It requires local prior authorization in the VA.

5. Levodopa/Carbidopa-intestinal gel formulation (Duopa®) is continually pumped for up to 16 hours per day into a percutaneous G-tube and provides sustained responses over conventional preparations. It requires local prior authorization in the VA.

6. Levodopa (Inbrija®) is an inhalable form of levodopa packaged in capsules that are used with an inhaler up to five times a day for OFF times. It requires local prior authorization in the VA.

b. COMT inhibitors
   1. Entacapone (Comtan®) improves levodopa bioavailability by inhibiting peripheral conversion into metabolites. Only works in presence of exogenously administered levodopa. Indicated for end of dose wearing off on standard levodopa preparations. Diarrhea may be a side effect that limits its use for some. It is on the VA formulary.

   2. Tolcapone (Tasmar®) is more potent than entacapone but rarely used due to need for liver enzyme monitoring due to rare complication of fatal hepatic necrosis. It is non-formulary in the VA.

   3. Opicapone (Ongentys®) is a newer COMT inhibitor that is dosed once daily and is non-formulary in the VA.

c. Dopamine Agonists-Treatment with dopamine agonists may result in fewer motor complications (wearing off, dyskinesia, on-off motor fluctuations) than levodopa at 4-year follow-up. Dopamine agonist treatment of PD patients requiring dopaminergic therapy is associated with more frequent adverse events including nausea, hallucinations, somnolence, impulse control disorders and edema than levodopa therapy. Agonists can be used as monotherapy in early PD or as a symptomatic adjunct to levodopa.

   1. Ropinirole (Requip®) is available in standard immediate release (IR) formulation that must be given at least three times per day (TID) and is on the VA formulary; and also available in extended release (XL) formulation that can be given once a day that is non-formulary in the VA.

   2. Pramipexole (Mirapex®) is available in IR formulation given TID that is on the VA formulary and also available in extended release (ER) formulation that can be given once per day that is non-formulary in the VA.
3. Rotigotine (Neupro®) is available as 24-hour transdermal application (patch). Application site reactions are common and may be reduced by applying patches to different skin sites. It is non-formulary in the VA.

4. Apomorphine (Apokyn®) is delivered as an intermittent subcutaneous injection and can provide rapid onset of relief from Parkinsonian symptoms with a magnitude akin to levodopa, however with a shorter duration of action. It requires local prior authorization in the VA.

5. Bromocriptine is not preferred due to ergot side-effects.

d. MAO-B Inhibitors (selective) extend levodopa’s duration of action by reducing the rate of breakdown.

   1. Rasagiline (Azilect®) has a mild symptomatic benefit and enhances levodopa preparations to improve wearing off similar to entacapone in adjunctive studies. There is no clear evidence of neuroprotection, although some studies indicate some possible role. It is on the National VA formulary.

   2. Selegiline (Eldepryl®) has a mild symptomatic benefit but no clear evidence of neuroprotection. It is on the VA formulary. Selegiline is also available as an orally dissolving tablet (Zelapar®) is that is non-formulary in the VA.

   3. Safinamide (Xadago®) has a mild symptomatic benefit by improving ON time but can worsen dyskinesias that is non-formulary in the VA.

e. Amantadine is mainly used to help dyskinesias as disease advances but sometimes used in early disease for tremor or other mild symptoms. It is non the VA formulary with restrictions. It is also available in two long-acting forms, Gocovri® and Osmolex ER® that are both non-formulary in the VA.

   f. Istradefylline (Nourianz®) is an adenosine receptor antagonist that improves motor symptoms of PD through a non-dopaminergic pathway and is indicated as adjunctive therapy for patients on levodopa with wearing off. Dyskinesias are a challenging side effect of its use. It is non-formulary in the VA.

   g. Anticholinergics

Trihexyphenidyl may be used as monotherapy or as a levodopa adjunct that is on the VA formulary. It can be good for tremor and dystonia but often not well tolerated due to (anticholinergic) cognitive and other side effects.

2. Treatment of Parkinson’s Disease with Motor Fluctuations and Dyskinesia.

   a. Treatment strategies for motor fluctuations:

   1. Increasing frequency of levodopa formulations or adding controlled release formulations of levodopa. Adding dopamine agonists, COMT inhibitors, MAO-B inhibitors or istradefylline can also treat motor fluctuations.
b. Medications to Reduce Dyskinesia:
   1. Amantadine is efficacious in reducing dyskinesia in PD.
   2. Clozapine is efficacious in reducing dyskinesia in PD.

c. Deep Brain Stimulation (DBS) of the Subthalamic Nucleus (STN)
DBS of the STN is efficacious for improving motor function and reducing motor fluctuations, dyskinesia, and antiparkinsonian medication usage in PD. Adverse events may limit application of this therapy. The preoperative response to levodopa is probably predictive of postsurgical improvement from STN DBS.

d. Deep Brain Stimulation of the Globus Pallidus internus (GPi)
DBS of the GPi is efficacious for motor symptom control to reduce motor fluctuations and dyskinesia in PD. Studies suggest motor improvements are equivalent with GPi or STN targets. The position of the PADRECC is that GPi and STN should be equally considered with final determination made based on the clinical profile of the patient and comfort of the surgeon.

e. Deep Brain Stimulation of the Ventralis Intermediate Nucleus of the Thalamus (Vim)
Less commonly used surgery for PD, considered to be likely efficacious as a symptomatic adjunct to levodopa by the Movement Disorder Society. Used mainly for control of drug-resistant tremor.

f. Unilateral Thalamotomy of Vim
Radiofrequency ablation surgery for PD is a lesioning procedure used for control of drug-resistant tremor. This is only approved for unilateral treatment. Focused ultrasound is a non-invasive approach to this same lesioning therapy and was approved for treatment of PD tremor in 2018.

g. Exercise Therapy and Speech Therapy
These therapies are likely efficacious in helping with motor function and speech in PD. Exercise is also recognized as the lone neuroprotective intervention to slow progression of PD.

h. Neuroprotective Therapies
At this time, there are no definitive pharmacologic therapies that are neuroprotective or slow down the progression of the PD. Agents that have been studied to date include Vitamin E, Riluzole, CoEnzyme Q10, Levodopa, Pramipexole, Rasagiline, Selegiline and Ropinirole.


   a. Depression-The Movement Disorders Society (MDS) considers pramipexole (dopamine agonist) efficacious for the treatment of depressive symptoms. Nortriptyline
and desipramine are tricyclic antidepressants (TCA) considered likely efficacious as well. As with all TCAs, caution is advised in patients with a history of urinary retention, angle-closure glaucoma or increased intraocular pressure, and cardiovascular disease. SSRI’s are most commonly used, and specifically it has been deemed that venlafaxine is efficacious for treatment of depression in PD. Citalopram, sertraline, fluoxetine and paroxetine have insufficient evidence to support their use. At the same time, given the favorable side effect and safety profile in this group of patients, they are widely chosen and used successfully. Cognitive behavioral therapy is a nonpharmacologic intervention and considered efficacious.

b. Psychosis -Clozapine is effective however safety monitoring to detect the rare incidence of agranulocytosis (0.38%) makes use of this drug difficult. Studies of olanzapine showed conflicting results against psychosis, but consistently showed motor worsening. Therefore, the MDS has deemed olanzapine unlikely efficacious and not useful. Quetiapine is possibly effective in the treatment of psychosis in the PD population, however methodologic problems and conflicting results amongst the studies evaluated led the MDS to deemquetiapine lacking in sufficient evidence to recommend. More recently pimavanserin (Nuplazid®), a selective 5-HT2A inverse agonist became the first FDA approved drug for the treatment of psychosis in PD. Its benefits as measured by Parkinson’s disease-adapted scales accrued over a 6 week period, with improvements in positive symptoms of psychosis as well as caregiver burden. It is considered efficacious by the MDS.

c. Dementia -Rivastigmine (Exelon®) is considered efficacious for treatment of PD dementia. Donepezil (Aricept®) and galantamine (Razadyne®) are also acetylcholinesterase inhibitors, but both have insufficient evidence to recommend their use. Worsening of tremor may be seen in some with use of this class. EKG monitoring for cholinergic effects is recommended, but not mandatory. Memantine (Namenda®) is not routinely used, given conflicting efficacy evidence in the literature.

d. Anxiety -Data regarding the treatment of anxiety in PD is insufficient.

e. Autonomic Dysfunction.

1. Orthostatic Hypotension (OH): There is insufficient evidence to recommend the use of indomethacin, fludrocortisone, pyridostigmine and domperidone in OH but in clinical practice use of fludrocortisone and/or midodrine in some patients has shown benefit. Droxidopa (Northera®) is FDA approved for the treatment of orthostatic dizziness, or lightheadedness in patients with neurogenic OH. It is a precursor of the neurotransmitter/hormone norepinephrine and is considered efficacious by the MDS.

2. Urinary Incontinence: There is no good evidence for pharmaceutical treatment of urinary symptoms in PD.

3. Gastrointestinal issues: Probiotics are considered efficacious for constipation in PD. Macrogol and lubiprostone are considered likely efficacious, while metoclopramide is considered unacceptable to PD patients due to motor worsening.
4. Sexual Dysfunction: Sildenafil citrate is considered efficacious for treatment of erectile dysfunction in PD.

5. Drooling: Consideration of botulinum toxin should be made in patients with PD and sialorrhea. Myobloc® or botulinum toxin type B, as well as type A (Botox®) has consistently shown benefit in studies to reduce drooling. Glycopyrrolate (1 mg bid) has been shown to significantly benefit sialorrhea over a one-week period. All three interventions are considered efficacious for treatment of sialorrhea in PD.

f. Sleep Dysfunction

1. Excess Daytime Somnolence (EDS): Conflicting results using modafinil (Provigil®) and caffeine to improve EDS have prompted the MDS to conclude there is insufficient evidence to recommend it. Careful evaluation should be undertaken to exclude other treatable causes of EDS such as sleep apnea.

2. Insomnia: Levodopa/carbidopa improves sleep-associated motor symptoms that may contribute to insomnia but there is insufficient data regarding improvement of objective tests of sleep. Melatonin is effective in improving a patients' perception of sleep quality but there is no clear evidence to recommend it from data of polysomnography. DBS may improve sleep quality in advanced PD patients but there is insufficient evidence to recommend it for treatment of sleep.

3. Restless Leg Syndrome/Periodic Limb Movements of Sleep. Alpha-2-delta agonists such as gabapentin and pregabalin should be considered as first line treatment for these disorders in PD. Use of levodopa or dopamine agonists are also effective for treatment of RLS/PLMD, but should only be considered when this is indicated for nocturnal motor symptoms of PD due to risk of augmentation of RLS symptoms.

4. REM Behavior Disorder (RBD). Data for treatment of RBD in PD is insufficient according to the AAN. Melatonin up to 15mg should be considered first line as it is the only intervention shown to restore REM atonia on polysomnography and has minimal side effects/interactions with other medications. Clonazepam is also considered a first line option, but should be used cautiously as it may worsen cognitive function over time. Acetylcholinesterase inhibitors are considered possibly appropriate in patients with cognitive dysfunction, though evidence is lacking for their use as primary agents.

5. Fatigue. Rasagiline was used in a small study and considered efficacious by the MDS for treatment of fatigue in PD. Methylphenidate or modafinil are considered to have insufficient evidence to support their use.

g. Impulse Control Disorders and Abnormal Repetitive Behaviors. Dosage decrease or elimination of dopamine agonists are a first line intervention. A small, controlled study of amantadine to treat patients with impulse control disorder that did not improve with agonist reduction or behavioral strategies showed significant
improvements. Due to lack of other evidence, the MDS considers this insufficient evidence to recommend amantadine.

8. NATIONAL VA PARKINSON’S DISEASE NETWORK
In 2003, the PADRECCs introduced the National VA Parkinson’s Disease Consortium Network (now known as the National VA PD Network) to promote Parkinson’s disease awareness and advocacy in the VA System. This initiative serves as a professional society to encourage training, mentorship, and networking. The Network is comprised of nationally dispersed VA physicians, nurses, pharmacists, social workers, physical and occupational therapists, and other allied health professionals. Members are provided with Parkinson’s disease educational offerings that include biannual national conferences, annual newsletters, bi-monthly electronic updates, monthly clinical conference calls and the Movement Disorders Series audioconference. In 2006, the philosophy of the Network was broadened with the creation of the Consortium Site Network (now known as PADRECC Associated Sites (PAS). These designated Sites are staffed by neurology clinicians with an interest and experience in the field of movement disorders. Over the years, several PAS have evolved into multidisciplinary clinics offering specialized care to Veterans with PD and movement disorders. In 2023, the Regional PD and Movement Disorder Centers were established to recognize sites offering expert PD and movement disorders care. The purpose of the Network is to ensure convenient specialty care to all Veterans, regardless of locality. There is at least one RPMDC in each VISN and several PAS dispersed throughout the United States. The PADRECCs oversee this program through administrative oversight, national education offerings and outreach, and professional mentorship and collaboration.

The National VA PD Network adds a grassroots tier to the PADRECC mission, thereby forming a “hub and spoke” model of national healthcare. The significance of this initiative was acknowledged in Public Law 109-461s6 (a)(1), Dec. 21, 2006 (Section 7329 38 USC) Veterans Benefits, Health Care, and Information Technology Act of 2006, which states that the PADRECCs must “jointly develop a consortium of providers with interest in treating neurodegenerative diseases, including Parkinson's disease and other movement disorders, at facilities without such centers in order to ensure better access to state-of-the-art diagnosis, care, and education for neurodegenerative disorders throughout the health care system of the Department.”

A. Designation of Regional Parkinson’s and Movement Disorders Centers RPMDCs are designated by the VISN Director, in collaboration with the Neurology NPED and National PADRECC Director.

RPMDC designation are dependent on several factors:

1. The RPMDC Director must be a neurologist with specialty fellowship or substantial experience in the management of patients with movement disorders.
2. The RPMDC has an established multi-disciplinary care team.
3. The RPMDC has the ability to offer specialized care such as chemodernervation therapy and DBS stimulation adjustments.
4. Support of their local VA administration.
5. Geographic location.

B. PADRECC Associated Site designation are dependent on several factors, the most important being the interest and availability of the Consortium Director. Other factors of consideration include the extent of movement disorders experience and current practice, support from the local VA administration, and the geographic needs of the Consortium network.

1. Complete application form and send to the address listed on the webpage.
   LINK: https://www.parkinsons.va.gov/docs/National_VA_Parkinson_Consortium_Membership_Application2.pdf

2. Application is reviewed and approved by the National PADRECC Director and the PADRECC Directors.

C. Scope of Services within the Network
   1. RPMDC have a multidisciplinary team offering specialty clinics for Veterans with Parkinson’s disease and related movement disorders in a regional capacity. Clinical services include evaluation and diagnosis, pharmacological treatment, non-pharmacological management, and referrals. Additional specialty services are available, including administration chemodenervation therapy and DBS stimulator programming. These clinics consult and collaborate with the PADRECCs to ensure modern and appropriate care for all affected Veterans.

   2. PASs offer specialized clinical care to Veterans with PD and related disorders. Clinical services include evaluation and diagnosis, pharmacological treatment, non-pharmacological management, and multidisciplinary referrals. These clinics consult and collaborate with the PADRECCs to ensure modern and appropriate care for all affected Veterans.

D. Veteran Referral to a RPMDC or PAS. Please refer to Section 10 of this document.

9. PD EDUCATION
The goal of PD 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 more diverse generation, many of 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.

Each PADRECC has either an Associate Director or Co-Associate Director of Education. These individuals are responsible for patient and professional education at their respective PADRECCs. Educational programs are planned based on the needs of
Veterans, their care providers and health care professionals. The Associate or Co-
Associate Directors are also members of the National VA Parkinson’s Disease Network
Education Subcommittee which meets virtually monthly to explore and coordinate ideas
related to national patient and professional education initiatives.

There are many opportunities to learn about PD etiology, pathology, disease
management, and multidisciplinary care team approach through the VA System. The
PADRECC and Consortium website (LINK: https://www.parkinsons.va.gov) offers
education materials and resources to health care professionals, Veterans, and families
regarding PD management, care recommendations, and services unique to VHA. These
educational resources are available for on-site training, mentoring, and consultation.

A. Professional education opportunities within the PADRECC network.
1. PD Consortium Meetings

The PADRECCs offer bi-annual conferences for Consortium participants with three
main purposes:
   a. To provide an educational update on PD research and state-of the art PD care
   b. Present opportunities for Consortium members to network and discuss
      collaborative education and research projects; and
   c. To offer information about the national non-profit Parkinson’s disease
      community organizations.

2. Movement Disorder Series
In partnership with VA Institute for Learning, Education and Development (ILEAD), each
year the PADRECCs sponsor two four-hour knowledge-based webinars to provide VHA
healthcare professionals with current practice standards and emerging trends in the
treatment of PD and other movement disorders. Continuing Education (CE) credits for
professionals is typically provided for the live webinars. The webinars are also recorded
and available for professionals who were not able to attend the live event (CE not
available for recorded program). The speakers are either PADRECC Directors, selected
researchers or clinicians with expertise in PD. Link: Movement Disorders Series -
Parkinson’s Disease Research, Education and Clinical Centers (va.gov)

3. Tele-Case Conferences
Each PADRECC conducts a regularly scheduled video-case conference with
geographical Consortium members. This serves as a platform for an educational
exchange amongst the providers regarding clinical aspects of PD, research topics, and
VHA patient care standards.

4. Clinic Based Education and Training
Clinical education and training is routinely provided at the PADRECCs to various local
health care professionals. These include nurses, allied health professionals, medical
students, and physicians in training (Fellows, Residents) from various disciplines
including Neurology, Psychiatry, Geriatrics, and Rehabilitation Medicine. Physician and
nurse day training programs are in place to meet the needs of Consortium members.
5. Formal Educational Programs (Lectures and Seminars) Each PADRECC sponsors educational programs including journal clubs, lectures, and seminars from local and guest faculty on PD and related movement disorders. Topics include information on diagnosis, medical and surgical treatments, epidemiology, rehabilitation (gait, motor control, exercise, balance, and innovative treatment interventions), quality of life issues, and non-motor symptoms of PD. Certificates of attendance and continuing education credits are provided as appropriate.

6. Collaboration with the Community
The PADRECCs collaborate with local nonprofit organizations (NPO) such as NPO PD-specific organizations in their community. This may include co-sponsoring conferences, providing speakers for their educational programs, and serving on the Board of Directors and/or educational committees. VHA/PADRECC and The Parkinson’s Foundation (PF) established a partnership in 2020 with the goal to improve the health, well-being, and quality of life of Veterans living with PD. Over the past 3 years this partnership as developed several Veteran specific resources and increased awareness of PF and PADRECC services throughout the VA as well as the country.

7. Educational Publications:
   a. The VA Parkinson Report. This annual newsletter for the PADRECCs and Consortium provides educational articles, news of the latest research, information for movement disorders specialists, and updates on PADRECC and consortium center activities LINK: https://www.parkinsons.va.gov/Consortium/Newsletter.asp.

   b. The Transmitter. This bi-monthly electronic publication includes a synopsis of PD research articles edited from leading neurology journals and other valuable information pertinent to PD. It also provides an update on PADRECC Committee activities, dates of upcoming movement disorders events, (Transmitter) LINK: https://www.parkinsons.va.gov/Consortium/Transmitter.asp

   1. One-on-one patient/provider education
   2. Education/Support Groups
   3. Formal Educational Events.
   4. Educational Publications

   c) PADRECC Local Newsletters- several PADRECCs publish local newsletters one to two times a year that provide PD education and resource information for veterans/families/supporters.

   d) Patient Education Brochures- developed by the PADRECCs to provide patients and families with information on the most common topics concerning PD. Topics include: Exercise and Physical Activity, Fall Prevention, Parkinson’s Disease Medications, Motor Symptoms of Parkinson’s Disease, Non-Motor Symptoms of Parkinson’s Disease, Agent Orange and Toxic Exposures & Parkinson’s Disease.
Brochures can be found on the National PADRECC website: LINK: www.parkinsons.va.gov/patients.asp

e) Suggested Education Essentials- is a document that has been reviewed by the PADRECC Education Committee and includes useful website links for topics such as: Overview of PD, Exercise, Medications, Nutrition, and National/Regional Organizations. LINK: https://www.parkinsons.va.gov/patients.asp

B. Patient education opportunities within the PADRECC network
Parkinson’s disease specific education is well integrated in the PADRECC operational structure and is routinely provided during all patient visits by educators, nurses, and physicians. Education covers all aspects of PD care and management including medications, diet, exercise, sleep, driving safety, and overall patient safety issues. In addition to face-to-face educational sessions, written materials developed within the PADRECC, Patient Education Brochures) or from well-respected sources (e.g., Parkinson’s Foundation) are also provided as additional resources for the patients, their families, and care providers, (Patient Resources). LINK: https://www.parkinsons.va.gov/patients.asp

Each PADRECC schedules formal educational programs for Veterans with PD and the community at large. These programs may include support groups, health fairs, formal conferences, and presentations by PADRECC neurologists and staff. Topics for these programs and presentation are typically based on medical and surgical aspects of PD management, including but not limited to: Deep Brain Stimulation, exercise, safety, research advances, and care giving challenges.

10. REFERRAL GUIDELINES
The goal of the PADRECC is to provide competent and convenient care to all Veterans with PD. For many patients, some care can be provided by their primary care provider in a local facility. Situations that may require transfer of care, either temporarily (for a consultation) or permanently to a PADRECC, RPMDC or PAS include, but are not limited to, the following:

a. Confirming a new diagnosis of PD;
b. Counseling a newly diagnosed patient on treatment options;
c. Managing complications of therapy such as dyskinesia;
d. Managing side effects or intolerance of medications;
e. Managing non-motor issues in PD;
f. Expanding the formulary options for PD patients;
g. Evaluating treatment failure and expanding the differential diagnosis to Parkinson-plus diagnoses;
h. Evaluating potential surgical treatment of PD; and Managing/Evaluating of implanted DBS patients for programming.

A. Referral Procedure/Protocol.
For a Veteran to be evaluated by a PADRECC or NVAPDN clinician, please follow the steps below:
1. The Veteran, caregiver, and/or VA primary care provider or neurologist should choose the preferred PADRECC to consult.
2. The VA primary care provider or neurologist makes the referral to the PADRECC using an inter-facility consult (IFC).
3. The Veteran or caregiver should receive a call from the PADRECC to schedule an appointment within 72 hours after the IFC has been received.

The Veteran, caregiver, or VA provider can seek assistance with this process by contacting the PADRECC/Consortium Hotline at 1-800-949-1001 x205769.