

Helping Those Who Serve: Parkinson's Disease Information For The Veterans Community



AMERICAN PARKINSON DISEASE ASSOCIATION (APDA) RESOURCES

APDA is here to help you on your Parkinson's disease (PD) journey. APDA's network provides information and referrals, education and support programs, health and wellness activities, and events to facilitate a better quality of life for the PD community. Search APDA's website by state to connect to an Information and Referral Center or APDA Chapter in your community at: www.apdaparkinson.org/resources-support/local-resources.

APDA also provides information and referrals that are specific to young onset PD. Generally speaking, people younger than 50 years of age who are diagnosed with PD are considered to have young onset PD. To speak with someone about young onset PD, contact: (800) 223-2732 or young@apdaparkinson.org.

APDA Rehabilitation Resource Center at Boston University was established to help people with PD access information on exercise recommendations. This center provides callers with an opportunity to speak with a licensed physical therapist who can answer questions about exercise and resources in the caller's area. Find out more at: www.bu.edu/neurorehab/resource-center or (888) 606-1688.

For information about services provided through the Veterans Health Administration for military veterans with PD, call (800) 223-2732.

APDA provides free online publications on a variety of topics at: www.apdaparkinson.org/resources-support/download-publications

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HELPING THOSE WHO SERVE: PARKINSON'S DISEASE INFORMATION FOR THE VETERANS COMMUNITY

Introduction

Parkinson's disease (PD) is a progressive neurologic disease that affects movement and other body functions. It causes tremors, slowed movements, and stiffness, and it may eventually impair the ability to stand upright and walk. PD can affect mood, thinking, sleep, and digestive function, as well as other functions; often, the symptoms worsen over time. Recognizing the importance of expert care in the treatment of PD, the Veterans Health Administration has created a nationwide network of treatment centers that specialize in the care of people with PD.

In this booklet, you will learn about PD, its symptoms, how it is treated, and the benefits available to you as a veteran of the United States armed services. You will also learn about the Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) created by the Department of Veterans Affairs (VA) as centers of excellence for PD treatment, as well as the national consortium of regional treatment centers. These centers are staffed by specialists in the treatment of PD, working as team members with a wide variety of other healthcare professionals to deliver a full range of services. Through this network of care centers, the VA is committed to providing veterans with PD with the best possible care throughout the course of their disease.

PD and Veterans

Veterans may be at an increased risk of PD because of their service. Evidence suggests that one cause of PD may be exposure to pesticides or herbicides. During the Vietnam War, many veterans were exposed to Agent Orange, a mix of herbicides that were used by the US military to defoliate trees and remove concealment for the enemy. There are other causes of PD as well, and most people who develop PD were never exposed to high levels of pesticides or herbicides.

In 2010, the VA added PD to the list of diseases with a presumptive service connection, based on the time and location of service. Veterans with PD from any branch of the military who were exposed to Agent Orange during service may be eligible for disability compensation and health care coverage from the VA. You don't need to prove you were exposed to obtain benefits. Exposure is presumed for those who served in locations and times that likely resulted in exposure. Full details are available on the Veterans Health Agency website at <http://www.publichealth.va.gov/exposures/agentorange/locations/index.asp>.

Free Agent Orange Registry Health Exam

If you served in Vietnam or another area where Agent Orange was sprayed, you may be eligible for an Agent Orange Registry health exam. You don't need to enroll in the VA's health care system to take part. Contact your local VA Environmental Health Coordinator about getting this health exam. You can find contact information on the Veterans Health Administration website at <http://www.publichealth.va.gov/exposures/coordinators.asp>.

If you have PD and don't meet the criteria for exposure, you may still obtain care through the VA. As detailed later in this booklet, the VA maintains a group of centers of excellence called Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) that specialize in PD, as well as a nationwide network of regional specialty clinics with expertise in PD. These centers provide expert diagnosis, treatment planning, multidisciplinary care, and support groups for people with PD at every stage of the disease.



ABOUT PARKINSON'S DISEASE

Parkinson's disease is a movement disorder, meaning it affects the ability to move and thus perform daily activities. It can also cause a wide range of "non-motor" symptoms that don't involve movement. PD is progressive, meaning the symptoms become worse over time. While no treatments can halt or slow the disease, there are a wide range of treatments for both motor and non-motor symptoms that can help you maintain a high quality of life for many years.

Most people who develop the symptoms of PD do so some time after the age of 50, but PD can affect younger persons as well. There are an estimated 1 million Americans living with PD, and more than 10 million people worldwide have PD.

Motor Symptoms of Parkinson's Disease

Motor symptoms, or those related to movement, are the most widely recognized consequences of PD. These include:

- **Tremor:** Tremor is a slow, rhythmic involuntary movement or shaking. In PD, tremor is most often seen when the affected limb is at rest, rather than engaged in a voluntary movement. The tremor usually begins in one hand, foot, or leg and over time affects both sides of the body.
- **Rigidity:** Rigidity refers to a tightness or stiffness of the limbs or torso. Rigidity, especially in the early stages of PD, may be mistaken for arthritis or orthopedic problems, such as a shoulder injury.
- **Bradykinesia** (slowed movements): PD causes a general slowness of movement, including slower limb movements, decreased blinking, and reduced fine motor skills. Movements are also reduced in magnitude, leading to small handwriting, a softer voice, and smaller steps.
- **Postural instability:** Over time, a person with PD will likely become less able to maintain balance, increasing the risk of falling.

- **Gait difficulties:** Bradykinesia and postural instability both contribute to gait (walking) difficulties in PD, particularly as the disease progresses. A person with advanced PD may experience episodes of freezing, in which he or she has difficulty initiating any movement.

Non-motor Symptoms of Parkinson's Disease

Non-motor symptoms of PD vary widely, and not all people with PD experience all of them. They include:

- **Depression and anxiety:** Depression and anxiety are common in PD. Both may respond to medication and/or psychotherapy.
- **Cognitive changes:** Particularly in more advanced PD or in older people with PD, problems with thinking, word finding, and judgment are common. If these symptoms occur in the early stages of illness, however, they may be symptoms of a related disorder (e.g., dementia with Lewy bodies) rather than PD. Confusion may also be a side effect of some PD medications.
- **Sleep disturbance:** Difficulty staying asleep is common in PD, leading to daytime sleepiness. Unfortunately, napping tends to make nighttime waking more likely. Vivid dreams may occur, often as a side effect of antiparkinson medications.
- **Orthostatic hypotension:** Orthostatic hypotension, or low blood pressure upon sitting up or standing, can cause dizziness, lightheadedness, and a risk for falling.
- **Weight loss:** Loss of weight is a common symptom of PD, particularly in the later stages of the illness. If weight loss is significant and unintended, your physician should perform an examination to exclude other medical causes of weight loss. While there can be a great deal of weight loss with PD, it will typically level off. There are different causes of weight loss in patients with PD, including decreased appetite,

swallowing difficulties, gastrointestinal problems such as chronic constipation, or depression. The constant motion of an advanced resting tremor or involuntary movements may burn many calories and can also be the cause of weight loss.

- **Gastrointestinal symptoms:** PD may cause constipation and problems with bowel motility. Reduced swallowing may lead to excess saliva accumulation and drooling. Difficulty swallowing in advanced PD increases the risk for choking on food.
- **Sexual symptoms:** Changes in sexual desire, or libido, are often under-recognized. Sexual desire may be reduced in some cases because of complex psychological issues. In other cases, a reduced libido can be a direct effect of PD. Treatment with PD drugs frequently improves sexual desire and, in some cases, can even increase it to a dysfunctional level. In men, the inability to achieve or maintain an erection (impotence) can occur; however, impotence may also be related to other age-related changes in the body or other conditions.
- **Urinary symptoms:** Urinary frequency (the need to urinate often) and urinary urgency (the feeling that one must urinate right away, even if the bladder is not full) are other possible symptoms of PD. These symptoms occur because the normal reflex mechanisms that control the bladder are disrupted. Urinary problems may be worse at night, when a person is lying flat. There may also be problems with initiating a urine stream (urinary hesitancy), slowness of urination, and overflow of the bladder. It should be noted that urinary symptoms in older men may be caused by an age-related enlargement of the prostate gland and not PD.
- **Other non-motor symptoms:** These may include fatigue, sweating, melanoma, hallucinations, and reduced sense of smell.

Diagnosis of Parkinson's Disease

There is no medical test that can definitively diagnose PD. Diagnosis should be made by a neurologist, and in many cases it is best done by a movement disorders specialist who has received extensive training in diagnosing and treating movement disorders, including PD.

Clinical diagnosis relies on a detailed medical and family history, a physical exam, a neurological exam that includes careful observation of movements and balance, and possibly some additional tests to rule out other conditions. Diagnosis requires the presence of at least two of the three core motor symptoms of tremor, bradykinesia, and rigidity.

A type of neuroimaging test called a dopamine transporter scan (DaTscan) may be used to rule out causes of tremor, including a disorder called essential tremor. However, this type of scan cannot distinguish between PD and some other conditions, such as multiple system atrophy and progressive supranuclear palsy, that cause the same type of brain changes as PD.

What Causes Parkinson's Disease?

PD is caused by the loss of neurons (nerve cells) in regions of the brain that control movements, as well as other regions controlling the non-motor aspects of the disease. The ultimate cause for this loss is unknown in most cases, but it is a subject of intense research. Most scientists believe that most cases of PD are due to a combination of genetic risk factors and environmental exposures. PD has been linked to pesticide and herbicide exposure, certain toxic metals, and other environmental poisons. In addition, several genes have been identified that increase the risk of PD.

The neurons that control movements rely on a chemical called dopamine to pass messages between them. Loss of dopamine in the brain accounts for most (though not all) of the symptoms of PD. Therefore, important components of the treatment strategy are to preserve dopamine or to mimic its effects. This is what many of the antiparkinson medications do.

Treatments for Parkinson's Disease

While no treatments can slow or stop the loss of neurons that causes PD, there are a wide range of treatments that can reduce both motor and non-motor symptoms. Treatment strategies in PD tend to change over the course of the disease as symptoms increase. Remaining active and otherwise healthy is an important part of treatment throughout the disease.

Non-pharmacological Treatments: Exercise, Daily Activities, and Non-medical Therapies

Starting or continuing a schedule of regular exercise can make a big difference in your mobility, both in the short and long term. Regular exercise routines of walking, strength training, or Tai Chi (a Chinese exercise and balance practice) can help to maintain—or even improve—mobility, balance, and coordination. Swimming, cycling, and dancing can provide benefits as well. Whatever you enjoy to stay mobile is the best activity for you, as you will be more likely to stay committed to it. Talk with your physician and a physical therapist about the best evidence-based exercise regimen, especially if you want to begin something new and challenging.

A physical therapist can help you individualize your exercise regimen to suit your needs and capabilities. An occupational therapist can help you make the most of your mobility in the activities of daily living, such as dressing, cooking, driving, or working. A speech and language pathologist can evaluate your speech and work with you to maintain voice volume, as well as to avoid swallowing problems. A dietitian can recommend changes in your diet to improve general nutrition and reduce constipation.





Medications for Parkinson's Disease

There are several types of medications for Parkinson's disease. They may be used individually or combined in order to best balance effective symptom control and to minimize side effects. Treatment is individualized depending on age, tolerance for side effects, disease progression, and other variables. Movement disorders specialists are often best equipped to tailor treatment to the individual patient. It is important to understand the potential side effects, as well as the potential benefits, of each medication. Your physician can provide you with this critical information.

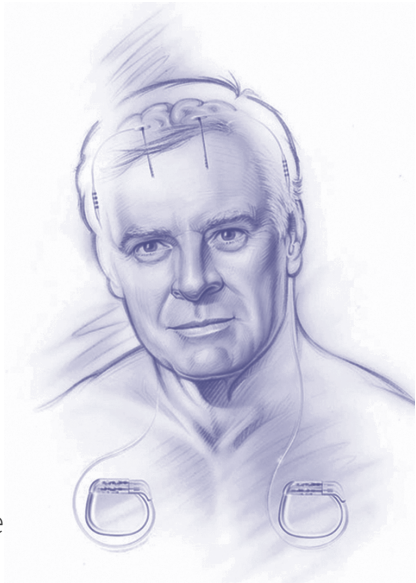
There are several treatment options for many of the most bothersome symptoms of PD including tremor, stiffness, slowness, mood problems and psychosis. PADRECC physicians have extensive training in deciding which medications would be appropriate for a given veteran.

For additional information on treatments for PD please visit APDA's website at <http://www.apdaparkinson.org/basic-info-about-pd/treatment/>.

Surgery for Parkinson's Disease

For most people with PD, medications provide good symptom control for years. As dopamine-producing brain cells are lost over the course of the disease, it is necessary to increase the dose of levodopa to maintain benefit, but this has the unfortunate effect of increasing the likelihood of developing dyskinesias, or abnormal movements. As dyskinesias become less tolerable, surgery called deep brain stimulation (DBS) may become a useful treatment option. DBS improves baseline symptom control, allowing for the use of a lower dose of levodopa.

DBS involves the implantation of permanent, thin electrodes into selected deep parts of the brain. One or two permanent battery-operated pulse generators, much like cardiac pacemakers, are then implanted under the skin of the chest or abdomen. The pulse generators are connected to the stimulator electrodes via wires, which are tunneled underneath the skin of the scalp and neck. Working continuously, the pulse generators are designed to suppress the motor symptoms of PD, thereby allowing for a reduction in medication, although most people who undergo DBS still need to take some PD medications. Adjustments to the pulse generators are individualized to achieve the best effect of DBS. The DBS procedure is associated with a small chance of infection, stroke, bleeding, or complications associated with anesthesia. A trained movement disorders specialist can determine if and when a person with PD is a candidate for DBS.



Support Groups

Participating in a support group can offer important benefits, from reducing the feeling of isolation that may come with a serious medical diagnosis, to practical tips from others going through the same experience. Support groups often include talks from medical experts who provide insight into new clinical studies going on in PD, or offer advice on managing common tasks that PD may impact. APDA sponsors PD support groups nationwide. Support groups may also be offered in your area through the VA.

Care Partner Support

People caring for those with PD also need support. If you are a care partner or you know someone who is, it is important to remember that the care partner must pay attention to his or her own physical and mental health. Many times, care partners overlook their own health, because so much time is spent caring for the person with PD. APDA's website has more information on care partner resources, including support groups and practical tips.

PD Care Through the Veterans Health Administration

The Veterans Health Administration (VHA) is committed to providing the highest quality of care to veterans with PD. Through the VHA, veterans with PD receive accurate and timely diagnosis, treatment, and support as they live with their disease.

The VA has created a nationwide network of treatment centers specializing in PD. This network is organized as a hub-and-spoke system, with six Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) and 51 Consortium Centers. Together, they provide expert PD care to veterans across the country.

PADRECCs

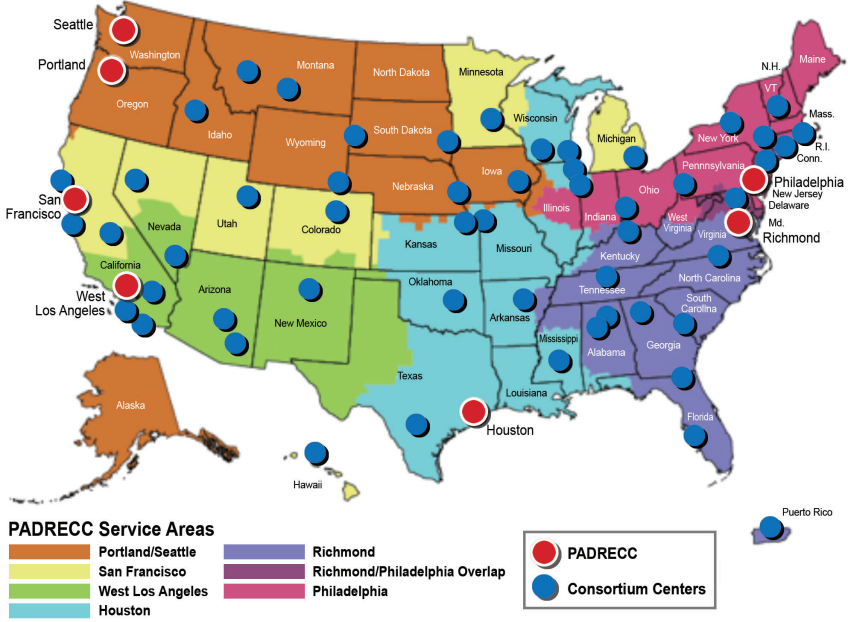
In 2001, the VA created six specialized centers known as the Parkinson's Disease Research, Education, and Clinical Centers or PADRECCs. These centers of excellence are designed to serve the estimated 80,000 veterans affected by PD through state-of-the-art clinical care, education, research, and national outreach and advocacy. The PADRECCs are located in Philadelphia, Richmond, Houston, West Los Angeles, San Francisco, and Portland/Seattle.

The PADRECCs are staffed by internationally known movement disorders specialists, neurosurgeons, psychiatrists, psychologists, nurses, researchers, educators, social workers, and other PD experts. The PADRECCs assist veterans in effectively managing PD and other movement disorders by offering VA pharmacy benefits, physical therapy, occupational therapy, speech therapy, medical equipment, surgical services, and other valuable resources.

As their name implies, the PADRECCs are devoted to research and education, as well as clinical care. Physician-scientists at each center carry out studies to understand more about PD and its treatment. The PADRECCs are actively involved in educational activities to raise awareness about PD and related movement disorders. Educational initiatives for patients and their families include but are not limited to monthly support groups, disease-focused conferences, and the distribution of educational materials.

Consortium Centers

A Consortium Center is a VA clinic that offers specialized PD and movement disorder specialty care to veterans who cannot travel to a PADRECC. These Centers are staffed by movement disorders specialists or clinicians with vast experience and/or interest in the field of movement disorders. Currently, 51 Consortium Centers work collaboratively with the PADRECCs to ensure the highest level of care for all veterans. Consortium Centers are distributed across the country, and there is a consortium center in almost every state.



Receiving care through a PADRECC or Consortium Center offers significant advantages. Management of PD is complex and is best done by a movement disorders specialist or a neurologist trained in PD treatment. The best treatment plan includes care from multiple specialists, including speech and language pathologists and physical therapists. Coordinating and providing this kind of multidisciplinary care is best done at a specialized center. VA centers also offer support groups and educational events, providing a comprehensive approach to PD care.

How to Get Care

You must be enrolled in the VA health care system to receive care through the PADRECCs or Consortium Centers.

First, choose a PADRECC or Consortium Center at which you would like to receive care. Then ask your VA primary care provider or neurologist to make a referral for you to that center. Finally, contact the PADRECC or Consortium Center to schedule an appointment. Be sure to allow at least 72 hours after your referring physician has sent the referral request.

Call the PADRECC/Consortium Hotline at 1-800-949-1001 ext. 5769 if you need assistance with this process. More information is available at the PADRECC/Consortium website:
<http://www.parkinsons.va.gov/index.asp>.

Suggestions for Further Reading

American Parkinson Disease Association (APDA). **Parkinson's Disease Handbook**. Available for download at apdaparkinson.org

This comprehensive handbook has been designed to help by providing valuable information about PD, including common symptoms, available treatments for disease management, practical tips on caring for someone with PD, and research currently underway in PD.

American Parkinson Disease Association. **Educational Supplements**. Available for download at <http://www.apdaparkinson.org>.

APDA publishes a wide range of brief publications on important topics about living with PD, including medical management, depression, exercise, and cognitive changes.

William Weiner, MD, Lisa Shulman, MD, and Anthony Lang, MD. **Parkinson's Disease: A Complete Guide for Patients and Families (A Johns Hopkins Press Health Book). Third edition.** Available from online booksellers.

Three top experts in the treatment of PD provide practical, detailed advice for patients and families on living with PD.

J. Eric Ahlskog, MD, PhD. **The New Parkinson's Disease Treatment Book: Partnering with Your Doctor To Get the Most from Your Medications. Second edition.** Available from online booksellers.

Dr. Ahlskog of the Mayo Clinic has three decades of expertise in treating PD. Here, he provides in-depth information for patients to help them be fully informed and a true partner in their own treatment.

K. Ray Chaudhuri, MD, FRCP, DSc, and Victor S. C. Fung, MBBS, PhD, FRACP. **Fast Facts: Parkinson's Disease.** Available from APDA.

This book provides up-to-date information on all aspects of PD at a level appropriate for medical professionals and educated lay people.

Jon Palfreman. **Brain Storms: The Race to Unlock the Mysteries of Parkinson's Disease.** Available from APDA.

This book provides an overview of the history of understanding of PD, and an update on the latest research into its causes and treatments.

GLOSSARY OF TERMS

Alpha-synuclein: a protein that builds up in certain nerve cells in certain brain regions of people with PD and related conditions

Amantadine: medication used to prevent or treat influenza that is also used to ease the tremor and rigidity of PD

Anticholinergics: a class of drugs often used for the management of PD, typically as complementary medications to other, standard PD therapies; used to reduce the tremor of PD or ease the problems associated with the wearing off of levodopa therapy

Bradykinesia: slowness of movement; a common motor symptom of PD

Carbidopa-levodopa: a combination medication commonly used to treat PD; intended to increase dopamine levels in the brain

Care partner: a person, such as a close family member or friend, who supports an individual with a chronic medical condition

Cognitive: pertains to thought processes, such as memory, attention, concentration, and judgment

Cognitive behavioral therapy (CBT): a form of psychotherapy used to treat depression that focuses on challenging unrealistic thoughts and replacing them with more realistic ones

COMT inhibitors: drugs that block catechol-O-methyltransferase (COMT), an enzyme that breaks down dopamine and levodopa; used in PD to prevent the breakdown of levodopa therapy before it reaches the brain

DaTscan: FDA-approved imaging test used to detect dopamine function in the brain; can help differentiate idiopathic PD from other disorders that cause tremor or other Parkinsonian syndromes

Deep brain stimulation (DBS): involves the use of embedded pulse generators to suppress the motor symptoms of PD, thereby allowing for a reduction in medication; surgical option for people with advanced PD who have tried a number of different medication regimens for their motor symptoms

Dopamine: a brain chemical (neurotransmitter) that enables movement; brain levels of dopamine fall in certain brain regions in people with PD

Dopamine agonists: drugs that mimic the action of dopamine

Dyskinesias: fragmented or jerky movements of the limbs or torso; often apparent at peak times of levodopa therapy in more advanced PD

Dysphagia: difficulty moving food from the mouth to the esophagus

Gait: pattern of walking

Idiopathic: of unknown cause

Impotence: the inability to maintain or achieve an erection

Lewy bodies: clumps of protein (alpha-synuclein) found in the nerve cells in certain brain regions of people with PD and related conditions

Libido: sexual desire

MAO-B inhibitors: drugs that block the enzyme monoamine oxidase B (MAO-B) in the brain; MAO-B breaks down dopamine

Motor symptoms: symptoms that primarily involve movement

Movement disorder: a neurological condition that affects movement

Movement disorder specialist: a physician, typically a neurologist, who has undergone further training to diagnose and treat movement disorders

Neurologist: a physician who is trained to diagnose and treat neurologic disorders

Neurotransmitter: a brain chemical that allows neurons to communicate with one another

Non-motor symptoms: symptoms that do not primarily involve movement

Oxidative stress: a destructive condition in which free radicals damage cells; associated with cell loss and aging

Parkinsonian syndromes: movement disorders that are not idiopathic PD but have some overlapping symptoms, such as rigidity and slowness of movement (bradykinesia)

Resting tremor: a tremor that occurs when still; a hallmark of PD

Rigidity: stiffness of the muscles

Tai Chi: a form of exercise developed in ancient China that can help with posture and balance

Tremor: a form of rhythmic shaking

Urinary frequency: the need to urinate often

Urinary hesitancy: difficulty initiating a urine stream

Urinary urgency: the feeling that one must urinate right away, even if the bladder is not full

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Veterans Health Administration. **Parkinson’s Disease and Agent Orange website.**

<http://www.publichealth.va.gov/exposures/agentorange/conditions/parkinsonsdisease.asp>

PADRECC information <http://www.parkinsons.va.gov/index.asp>

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