AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

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: apdaparkinson.org/community.

A Closer Look Blog, by Dr. Rebecca Gilbert, APDA Vice President and Chief Scientific Officer, aims to address both timely and timeless topics related to PD. In addition, the blog focuses on practical, take-home tips that can be gleaned from the information discussed. apdaparkinson.org/doctor-blogs/a-closer-look.

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: 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.

In addition, recently, the U.S. Department of Veterans Affairs (VA) issued a ruling making it easier for certain former service members with Parkinson's disease (PD) to receive disability benefits. The decision applies to individuals who were exposed to contaminants at Camp Lejeune and later developed PD. As a part of the Caring for Camp Lejeune Families Act of 2012, qualifying Veterans can receive all their health care (except dental care) from VA if they served on active duty at Camp Lejeune for at least 30 days between August 1, 1953 and December 31, 1987, even if they don't have a health condition that is presumed to be related to exposure. Parkinson's disease is one of the 15 conditions.

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 overfill 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

Once you are diagnosed with PD, your focus should be on improving your symptoms and maintaining an active and positive lifestyle. Although there is currently no cure for PD, it is possible to successfully manage symptoms through healthy choices, medications, and, in some cases, surgery.

Treatment needs change over the course of the disease. At every stage, it is important to maintain physical activity, eat a healthy diet, and pay attention to your mental health. Early treatment with medication can help most people with PD maintain an active lifestyle and continue working. Medications are adjusted throughout the course of the disease, in order to maintain the best control of symptoms and avoid major side effects. Adjusting medications can be complex, and is one of the best reasons to be seen by a movement disorders specialist.

LIVING WITH PD

Living with PD involves addressing symptoms through:

- **Lifestyle, including regular exercise and a healthy diet**
- **Medications and other treatments**
- **A supportive social network**
- **A strong partnership with your healthcare team**

Daily Living

Exercise and Daily Activity

In the management of PD, your lifestyle is one of the first things on which you will want to focus. Starting or continuing a schedule of regular exercise can make a big difference in your mobility, both in the short and long term. In fact, several research studies have shown that regular exercise routines of walking, strength training, or **Tai Chi** can help to maintain, or even improve, mobility, balance, and coordination in people with PD. People with PD also report the physical (and mental) benefits of swimming, cycling, dancing, and even non-contact boxing. Whatever you enjoy to stay mobile is the best activity for you, as you will be more likely to stay committed to it. Generally speaking, in the case of PD, the more active you are, the more active you'll stay.

If you did not exercise regularly before your diagnosis, or if you are unsure about your level of fitness or stamina, talk to your primary care physician first. It's important to have your overall health, and specifically your cardiac status, evaluated before starting any new exercise regimen. Also, a physical therapist is a great resource for finding out what your body can tolerate and what you can do safely on a regular basis. Your primary care physician or neurologist can provide you with a referral to a physical therapist. Regardless of your level of fitness, an early evaluation by a physical therapist can be very valuable. Among other benefits, a physical therapist can help you individualize your exercise regimen to suit your needs and capabilities.

The APDA Rehabilitation Resource Center at Boston University was established to help people with PD access information on exercise recommendations. This center provides callers 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**.

In addition to physical therapists, occupational therapists can help people with PD better manage their daily activities, particularly as the disease progresses. Occupational therapists can help you make the most of your mobility with any number of daily activities—whether it's writing, typing, cooking, driving, bathing, dressing, or grooming. Modifications for work and to the workplace environment also fall under the expertise of the occupational therapist.

A speech and language pathologist will evaluate and treat changes in voice volume and speech patterns. The Lee Silverman Voice Treatment (LSVT) program, an **evidence-based** therapy to increase loudness, is provided by many practitioners. A symptom that may develop as PD advances is **dysphagia** (dis-FAY-jyah), or difficulty swallowing. This requires careful assessment and treatment to avoid complications due to swallowing problems. Speech-language pathologists can help treat swallowing difficulties.

Diet

There is no one diet that is recommended for PD, but healthy eating in general is always a good choice. For example, eating several servings of fruits and vegetables a day increases fiber intake and can help alleviate constipation, in addition to promoting general health. Also, drinking plenty of water or other non-alcoholic and caffeine-free beverages ensures adequate hydration and may reduce the likelihood of low blood pressure and constipation.

There is evidence that the Mediterranean diet is heart- and brain-healthy and may be a good place to start when deciding on food options. This diet is characterized by vegetables, fruits, whole grains, legumes and nuts, moderate amounts of low-fat proteins such as chicken and fish and fats centered around olive oil.

Registered dieticians are great resources for reviewing your diet and making recommendations about healthy foods and daily calorie counts. A balanced diet should ensure that you get the recommended daily supply of vitamins to maintain your overall health. There is currently no evidence resulting from a well-designed trial in PD patients that a specific vitamin or nutritional supplement is useful in the management of PD, but research is actively ongoing in this area. Depending on your bone health, however, your primary care physician may recommend vitamin D and/or calcium supplements.

There has been much attention given to the possibility that **antioxidants** prevent or slow the progression of PD. Antioxidants are substances that remove toxic **free radicals**, which are produced by cells in the body during injury or stress. In cells, these free radicals promote something called **oxidative stress**, a condition associated with cell loss and aging. The overproduction of free radicals and oxidative stress may also contribute to the development of PD. Antioxidants, such as vitamin E and coenzyme Q10, remove free radicals to reduce the effects of oxidative stress. However, a large study published in the early 1990s showed that supplemental vitamin E did not slow the progression of PD; in fact, people with PD who took supplemental vitamin E fared worse than those who did not. As a result, supplemental vitamin E is not recommended for people with PD. In addition, another study showed that coenzyme Q10 did not provide any clinical benefit to people with PD over a placebo (sugar pill). Nevertheless, antioxidants obtained through your diet may still be beneficial, and research in this area continues.

AN EYE ON ANTIOXIDANTS

The following "super foods" contain high levels of antioxidants and other important vitamins:

- **Grapes**
- **Blue and red berries**
- **Nuts**
- **Dark green vegetables, such as spinach, broccoli, and kale**
- **Sweet potatoes and carrots**
- **Tea, especially green tea**
- **Whole grains**
- **Beans, such as soybeans, lentils, and black-eyed peas**
- **Fish, such as tuna, salmon, and sardines**

Depending on your prescribed medications, you may need to adjust your diet further. Your physician and pharmacist will tell you if your medications need to be taken at certain times of day or with or without certain foods or beverages. In some people with PD, dietary protein (e.g. yogurt, meat, etc.) may affect the absorption of levodopa (LEE-voe-DOPE-ah), a common treatment for PD. In addition, if you are taking medications that include levodopa, you may need to adjust the time that you take iron supplements (if you take them), because these supplements can affect the absorption of levodopa from the gastrointestinal tract.

Medications for the Motor Symptoms of PD

Although there is no cure for PD, there are several classes of medications available for the successful treatment of motor symptoms throughout the course of the disease. Be sure to talk with your general neurologist or **movement disorder specialist** about your most troubling symptoms and your goals for medical therapy. Some medications work better than others for specific symptoms of PD. Make sure you provide your physicians with a complete list of medications (both prescription and over-the-counter) and any vitamin or nutritional supplements that you may be taking.

The benefits of medications can only be obtained if you have access to them and take them as directed. Some medications for PD are available in generic forms or through special programs, so that they are more affordable. Some medications for PD are available in extended release or other forms, which allows for less frequent or easier dosing. Talk to your general neurologist or movement disorder specialist about your situation as well as any preferences for obtaining and taking your medications. Remember that it is important to review with your prescribing physician or pharmacist the side effects of all of your medications, both prescription and over-the-counter, and how they may interact with your other medications or alcohol. Nurses, physician assistants, and pharmacists are also extremely valuable sources of information regarding all of your medications, including how they should be taken, their side effects, and how they may interact with other medications.

A Word About Motor Complications

Motor complications refer to disease-related and treatment-related difficulties that typically develop after several years of uncomplicated treatment of PD. As the disease progresses, a person with PD may begin to develop **"off" time**, when their medications are not sufficient to maintain good symptom control throughout the day. Doses and timing can usually be adjusted, and new medications added, to reduce off time.

In advanced disease, off periods may become unpredictable and less responsive to medication changes.

Levodopa treatment increases the risk for development of **dyskinesias** [dis-keh- NEE-zhee-ahs]), which are uncontrolled movements, especially at the time of peak symptom control from a levodopa dose. Dyskinesias may not be troublesome, and many people with PD report they prefer some dyskinesia with good symptom control to no dyskinesia with less complete symptom control. Sometimes, however, dyskinesias can be socially distressing and/or disabling. Development of significant dyskinesias is often the point at which surgery is considered.

Wearable technology refers to devices worn by a patient that capture movement information. These devices can help monitor motor fluctuations and help with medication management.

Carbidopa-levodopa **(Sinemet®, Rytary®, Parcopa®, generics)**
The most effective treatment for PD is the combination medication of **carbidopa-levodopa** which is intended to increase brain levels of dopamine, that are deficient in people with PD. Levodopa, which is converted to dopamine in the brain, increases brain levels of dopamine. Levodopa reduces tremor, stiffness, and slow movement in people with **idiopathic** PD. Carbidopa prevents levodopa from being broken down in the body before it reaches the brain. Therefore, the addition of carbidopa allows levodopa to get into the brain more efficiently. Available in various strengths and delivery systems, carbidopa-levodopa is typically started at a low dosage to avoid nausea and vomiting, which can occur when the dose is increased too rapidly. The dosage is then increased over time as tolerated and until optimal therapeutic benefits are experienced. Carbidopa-levodopa is available in the United States as an immediate-release tablet (Sinemet® and generic), two types of extended-release formulations (carbidopa/levodopa ER available only in the generic version and Rytary®), and an orally disintegrating tablet (Parcopa®).

Side effects of carbidopa-levodopa treatment include nausea, orthostatic hypotension, sleepiness (which can be sudden, called sleep attacks), impulse control behaviors, hallucinations, and confusion. Levodopa also contributes to the development of dyskinesias.

Levodopa alone is also available in an inhaled version (Inbrija®), to be used as needed if PD symptoms re-emerge even though patients are taking doses of carbidopa-levodopa regularly.

The side effects of levodopa alone are similar to those of oral carbidopa-levodopa however, Inbrija® is not recommended in patients with COPD or asthma.

Carbidopa-levodopa Infusion **(Duopa™)**

An alternative form of carbidopa-levodopa (Duopa™) was approved by the FDA in 2015. It is intended for people with more advanced disease, whose symptoms are no longer responding well to oral carbidopa-levodopa. Instead of taking a pill, people with PD can receive carbidopa-levodopa in a gel form through an infusion pump. The pump delivers the medication directly into the small intestine through a surgically placed tube. The advantage of a continuous infusion of the carbidopa-levodopa is less immobility or “off” time from levodopa.

The side effects of the carbidopa-levodopa infusion are similar to those of oral carbidopa-levodopa, but may be associated with a higher incidence of peripheral neuropathy (numbness or loss of sensation in the fingers or feet).

Dopamine Agonists: Pramipexole **(Mirapex®, Mirapex ER®),** ***Ropinirole*** **(Requip®, Requip XL®),** ***Rotigotine*** **(Neupro®),** ***Apomorphine*** **(Apokyn®)**

Dopamine agonists are a little different from carbidopa-levodopa in that, instead of increasing dopamine levels in the brain, they mimic the activity of dopamine. They can be given alone in the early stages of PD, or as an adjunct to carbidopa-levodopa or other PD medications later on. Dopamine agonists are available in immediate-release as pramipexole (Mirapex®) and ropinirole (Requip®) or extended-release pramipexole (Mirapex ER®) and extended-release ropinirole (Requip XL®) formulations. One of the dopamine agonists, rotigotine (Neupro®), is available as a skin patch. As with carbidopa-levodopa, dopamine agonists are typically begun at a low dosage and titrated upward as tolerated and until optimal therapeutic benefits are experienced.

Apomorphine hydrochloride injection (Apokyn®) is a dopamine agonist, but its effect is very quick and brief. A so-called rescue medication, Apokyn® is reserved for people with advanced PD who have trouble with severe immobility or "off" periods during levodopa therapy. Apokyn® is given as an under-the-skin injection, often by a **care partner**.

The side effects of dopamine agonists are similar to those of carbidopa-levodopa, although impulse control disorders and sudden onset of sleepiness can be more pronounced. Apokyn® in particular can cause severe nausea, so it must be given with a medication that reduces or prevents nausea.

COMT Inhibitors: Entacapone **(Comtan®),** ***Tolcapone*** **(Tasmar®)**

COMT inhibitors are sometimes used with carbidopa-levodopa. Like carbidopa, they prevent the breakdown of levodopa before it reaches the brain. The result is that a more reliable supply of levodopa enters the brain, where it can be converted to dopamine. COMT (catechol-O-methyltransferase) inhibitors are typically prescribed to treat frequent "off" times with levodopa therapy. The COMT inhibitor entacapone (Comtan®) is available as a combination pill with carbidopa-levodopa (Stalevo®).

Sometimes COMT inhibitors can increase the side effects associated with levodopa therapy. Other common side effects of COMT inhibitors are abdominal pain, diarrhea, and discolored bodily fluids such as urine. Regular blood tests for liver function are required with the use of tolcapone (Tasmar®).

Selective MAO-B Inhibitors: Rasagiline (Azilect®), *Selegiline* (Eldepryl®, Zelapar®), *Safinamide* (Xadago®)

Selective MAO-B inhibitors block the MAO-B enzyme in the brain, which breaks down dopamine. This is another way to increase dopamine levels in the brain. MAO-B inhibitors can be used alone or with other PD medications. Selective MAO-B inhibitors may be prescribed to complement carbidopa-levodopa therapy, particularly if individuals experience "wearing-off" symptoms while taking levodopa. The selective MAO-B inhibitors for PD are available as a swallowed pill rasagiline (Azilect®) and selegiline (Eldepryl®) or an orally disintegrating tablet of selegiline (Zelapar®). Safinamide (Xadago®) is approved as an add-on therapy to carbidopa/levodopa for the treatment of "off" time. It is an MAOB inhibitor, but has other mechanisms of action such as inhibition of glutamate release.

Side effects of selective MAO-B inhibitors include mild nausea, dry mouth, lightheadedness, constipation, and, occasionally, hallucinations and confusion. Previous restrictions on the intake of foods containing tyramine (for example, aged cheeses, red wine, and draft beers) with selective MAO-B inhibitors have been relaxed by the FDA. However, MAO-B inhibitors can interact with other medications, such as certain antidepressants, nasal decongestants, and narcotic pain medications. Your physician or pharmacist can help you to understand these potential interactions.

Anticholinergics: Benztropine (Cogentin®), *Trihexyphenidyl* (Artane®)

Anticholinergics are often used for the management of PD as adjunct medications to other PD therapies. Anticholinergics are frequently prescribed to reduce the characteristic tremor of PD or to ease the problems associated with the wearing off of levodopa therapy.

Common side effects of anticholinergics include confusion, hallucinations, constipation, dry mouth, and urinary problems. As a result, the use of anticholinergics is typically limited to younger people with PD (under the age of 70). These anticholinergics should also be avoided in combination with antihistamines, certain psychiatric drugs, and alcohol.

Amantadine Formulations

Also used to prevent or treat influenza, **amantadine** (Symmetrel®) has been observed to ease the tremor of PD as well as muscle rigidity. It is typically used as an adjunct medication to other therapies for PD. In addition, it is used to decrease dyskinesia or involuntary movements caused by levodopa. Common side effects include lightheadedness, dry mouth, constipation, vivid dreams, lacy rash, typically on the legs, and swelling of the ankles. Amantadine dosing needs to be decreased in those with kidney disease. It may also interact with or enhance the side effects of anticholinergics and levodopa therapy. Amantadine is available in pill and syrup forms.

Two amantadine extended-release formulations are available. Gocovri® is taken once daily at night and is indicated for the treatment of levodopa-induced dyskinesias. It also has been shown to reduce “off” time. Osmolex ER™ is taken once daily in the morning and is indicated for the treatment of PD motor symptoms.

Adenosine inhibitors: Istradefylline (Nourianz™)

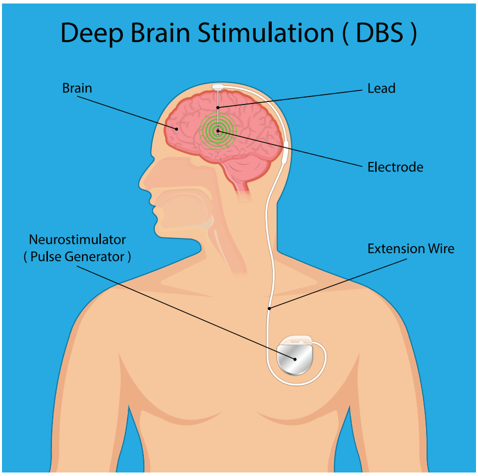
Adenosine inhibitors block the effects of the adenosine receptor. Like dopamine, adenosine is a **neurotransmitter** that works in the basal ganglia, the deep structures of the brain that are affected in PD. However, to some degree, adenosine and dopamine have opposite effects, so that *inhibiting* the adenosine receptor improves motor function. Istradefylline is indicated for use as an add-on treatment to carbidopa/levodopa for those experiencing “off” episodes.

Surgery

Deep Brain Stimulation

Deep brain stimulation (DBS) is a neurosurgical procedure for people with advanced PD who retain a good response to levodopa, but who have developed significant motor fluctuations including dyskinesias. DBS may also be used to treat medication resistant tremor. By stimulating specific points in the motor control circuits in the brain, DBS “rebalances” the circuits, restoring normal movement control to some degree. In most cases, this allows the person with PD to reduce their dosage of levodopa, and thus reduce their dyskinesias, while maintaining good symptom control.

DBS involves the implantation of permanent, thin electrodes into selected deep parts of the brain. A battery-operated pulse generator, much like a cardiac pacemaker, is implanted under the skin of the chest or abdomen. The pulse generator is connected to the stimulator electrodes via wires, which are tunneled underneath the skin of the scalp and neck (see image below). The DBS procedure is associated with a small chance of infection, stroke, bleeding, or complications associated with anesthesia.



The equipment is not visible underneath the clothes, and causes no discomfort in daily use. The electrodes are programmed by a remote computer for maximum symptom control, and the batteries can be replaced by an outpatient procedure when necessary, typically after several years.

DBS technology is constantly evolving with the development of rechargeable batteries which last much longer than a traditional battery, as well as more sophisticated programming options to maximize symptom control. The newer DBS systems are also MRI-conditional and can be placed in MRI-mode for the duration of an MRI, making the process of getting an MRI with a DBS system in place much simpler than with older systems.

Focused Ultrasound

Focused ultrasound (FUS) is a procedure that uses targeted ultrasound waves to heat up and lesion a precise location in the brain. By destroying a very specific area of the PD brain, the normal circuitry in the brain can be restored. Focused ultrasound is currently approved for treatment of tremor in PD.

Treatments for Non-Motor Symptoms of PD

People with PD commonly experience non-motor symptoms, including orthostatic hypotension, cognitive difficulties, hallucinations, depression, anxiety, sleep problems, or other difficulties. If you are experiencing any of these problems, be sure to discuss them with one or more members of your healthcare team. Additional therapies or medications (beyond those that treat the motor symptoms of PD) may be useful and can be taken in conjunction with your PD medications.

Medications Approved for Non-Motor Symptoms of PD

Droxidopa (Northera™) is specifically indicated to treat the orthostatic hypotension of neurologic diseases like PD. It should be used with caution in people with cardiac disease, as it may aggravate certain cardiac conditions. Common side effects include headache, dizziness, nausea, hypertension, fatigue, fever, and confusion. In addition, high dosages of carbidopa-levodopa may interfere with the activity of droxidopa. Other medications used to treat orthostatic hypotension are **fludrocortisone** (Florinef®) and **midodrine** (ProAmatine®).

Pimavanserin (Nuplazid™) is approved to treat hallucinations and delusions that may develop in advanced PD. It can cause swelling of the ankles, constipation, and confusion. Those with heart rhythm disturbances should avoid taking this medication.

Rivastigmine (Exelon®) is approved for dementia associated with PD. It can cause nausea, vomiting, and loss of appetite.

Complementary Therapies for PD

A vast array of complementary treatments for PD are available including meditation, massage, acupuncture, music therapy, and art therapy. Many of these therapies have been studied formally in PD, although usually in only small groups of people. Therefore, much is unknown about whether these therapies are truly effective and if so, how they work and how to maximize their benefit. Nevertheless, you may find them beneficial in addition to evidence-based medicines approved for PD. You should discuss the possible pros and cons of these options with one or more members of your healthcare team.

Many states have legalized medical marijuana and PD patients have tried it for relief of some of the motor and non-motor symptoms of PD. There is limited research however, investigating which PD symptoms respond to medical marijuana, as well as what type, delivery system, and dose should be used. There are also side effects of medical marijuana that must be considered including dizziness and low blood pressure. You should discuss the use of medical marijuana with your healthcare team as you would any other medication.

Research in PD is ongoing, and new treatments are on the way.

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

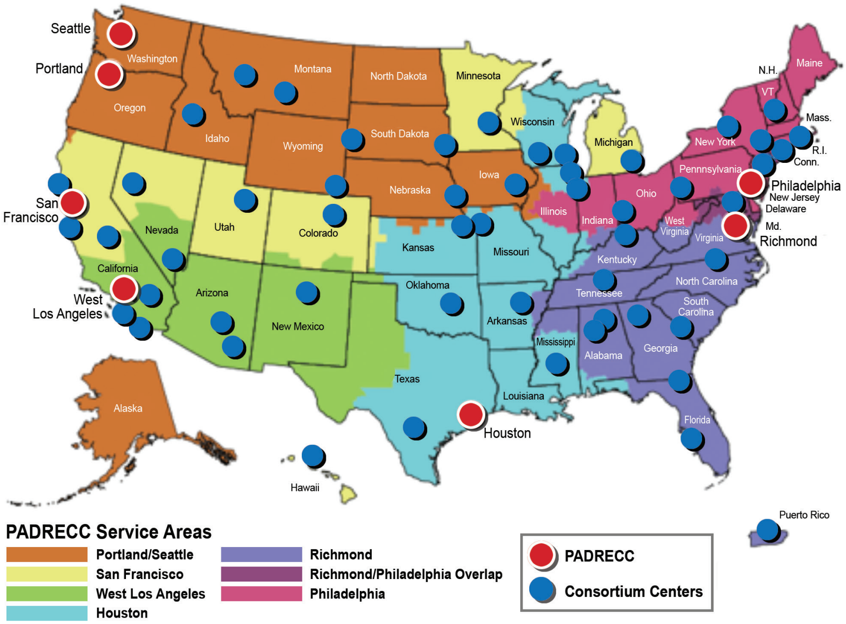
In 2001, the VA created six specialized centers known as the Parkinson's Disease Research, Education, and Clinical Centers or PADRECCs. These centers of excellence are designed to serve the estimated 80,000 veterans affected by PD through state-of-the-art clinical care, education, research, and national 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

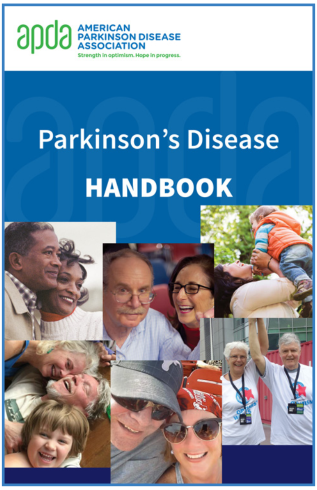
You must be enrolled in the VA health care system to receive care through the PADRECCs or Consortium Centers.

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/handbook-download/.



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 apdaparkinson.org/resources-support/download-publications/.

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

Resources

APDA is here to help you to live with Parkinson's disease (PD). The APDA 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 the APDA website by state to connect to an Information & Referral (I&R) Center or APDA Chapter in your community at:
apdaparkinson.org/community/
(800) 223-2732

APDA Rehabilitation Resource Center at Boston University was established to help people with PD access information on exercise recommendations. This center provides callers 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
(888) 606-1688

For information about services provided through the Veterans Health Administration for military veterans with PD, call:
(800) 223-2732
apdaparkinson.org/resources-support/national-veteran-resources

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A Closer Look Blog, by Dr. Rebecca Gilbert, APDA Vice President and Chief Scientific Officer, aims to address both timely and timeless topics related to PD. In addition the blog focuses on practical, take-home tips that can be gleaned from the information discussed.
apdaparkinson.org/doctor-blogs/a-closer-look/

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

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

Antioxidants: substances found in certain foods and supplements that may remove toxic free radicals from the body

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

Evidence-based: use of the best scientific evidence from clinical research to optimize clinical decision making

Focused ultrasound: a procedure that uses targeted ultrasound waves to heat up and lesion a precise location in the brain

Free radicals: toxic substances that are produced by cells in the body during injury or stress

Freezing: involuntary inability to move; frequently "freezing of gait," where the person with Parkinson's wants to walk forward but their feet feel stuck to the ground

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 complications: disease- and treatment-related complications, including off periods, dyskinesias, and other phenomena, that develop after several years of treatment

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

Off time: periods when treatments are not providing control of symptoms

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

Wearable technology: devices worn by a patient that capture movement information

REFERENCES

John Duda, MD, and Richard Robinson. **Diagnosing and Managing Parkinson's Disease: Practical Strategies for the Federal Healthcare Professional.**
http://www.parkinsons.va.gov/clinicians.asp linked to: https://www.med-iq.com/files/cme/presentation/pdfs/id_539_936.pdf

American Parkinson Disease Association. **Parkinson's Disease Handbook.**
apdaparkinson.org/handbook-download/.

Veterans Health Administration. **Parkinson's Disease and Agent Orange website.**
http://www.publichealth.va.gov/exposures/agentorange/conditions/parkinsonsdisease.asp

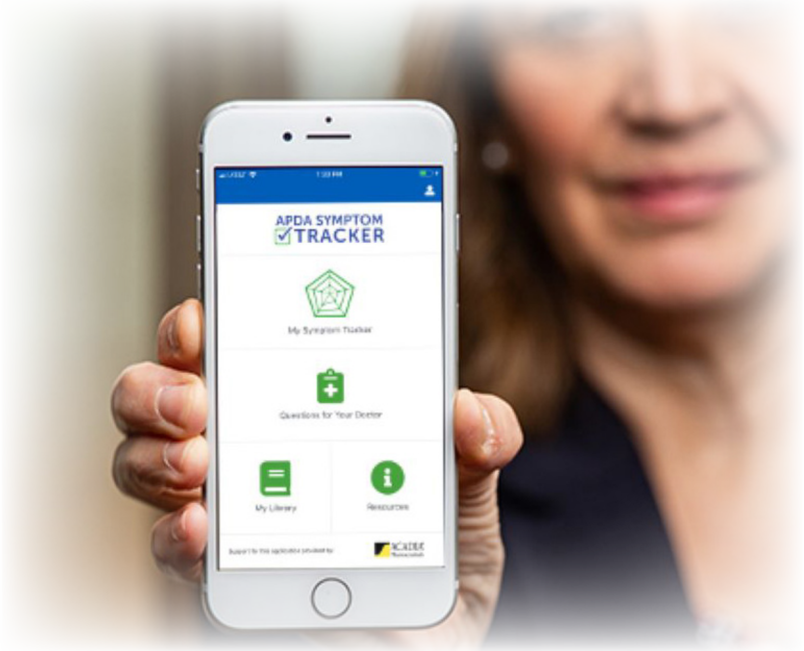
PADRECC information http://www.parkinsons.va.gov/index/asp

The information contained in this booklet is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician.

Notes

Notes

APDA SYMPTOM TRACKER



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