# Parkinson's Foundation FAQ



### **FREQUENTLY ASKED QUESTIONS:**

For Veterans With Parkinson's Disease and Their Care Partners





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### FREQUENTLY ASKED QUESTIONS:

For Veterans With Parkinson's Disease and Their Care Partners

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### PART 1: Overview of Parkinson's Disease

#### What is Parkinson's disease?

Parkinson's disease is a progressive, neurological disorder that occurs when the cells in the brain that make dopamine start to die. The rate of progression and symptoms are different for everyone. <u>Motor (or movement)</u> <u>symptoms</u> can include tremors, slowness of movement, and problems with balance. <u>Nonmotor (or non-movement) symptoms</u> can include low blood pressure, depression, anxiety, and problems with sleep.



#### What is Parkinsonism?

Parkinsonism is a term used to describe the collection of signs and symptoms found in Parkinson's disease and related disorders. These include slowness, stiffness, tremors and imbalance.

#### Where can I find resources for someone newly diagnosed with Parkinson's?

The Parkinson's Foundation has resources and materials designed specifically for a person newly diagnosed with Parkinson's. Read the <u>Newly Diagnosed Kit</u>, visit <u>Parkinson</u>. <u>org/NewlyDiagnosed</u> or call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636).

#### Around what age are people diagnosed with Parkinson's disease?

The average age of diagnosis for Parkinson's is 60. Older and younger people can also develop Parkinson's. When diagnosed at age 50 or younger it is known as <u>Young Onset</u> <u>Parkinson's disease</u>.

#### What causes Parkinson's disease?

The exact cause of Parkinson's disease is unknown. Scientists believe that genetics and the environment play a significant role. Genetics cause 10-15% of all Parkinson's.



#### Does Parkinson's disease run in the family?

In some families, changes in certain genes (called gene mutations) are inherited or passed down from generation to generation. Genetics cause 10-15% of all Parkinson's.

#### Is there genetic testing for Parkinson's?

While there is no genetic test to diagnose Parkinson's disease, there are tests to determine whether one carries specific Parkinson's <u>gene</u> **mutations. PD GENEration: Mapping the Future** 

of Parkinson's Disease is a national initiative that offers genetic testing for clinically relevant Parkinson's-related genes and genetic counseling at no cost for people with Parkinson's. For more information and to enroll, visit Parkinson.org/PDGENEration.

#### How many people have Parkinson's disease?

There are approximately 10 million people worldwide and one million in the United States living with Parkinson's disease. Each year approximately 60,000 people in the U.S. are newly diagnosed with Parkinson's. There are approximately <u>110,000 veterans</u> with PD who receive treatment through the U.S. Department of Veterans Affairs (VA).

#### How does Parkinson's disease progress?

No one can accurately predict the progression of Parkinson's for any individual, but the disease will advance over time. Usually motor symptoms, like <u>tremors</u>, slowness of movement, and <u>rigidity</u>, start on one side of the body and move to the other side over time. <u>Balance</u> later becomes a problem, and non-motor symptoms like <u>depression</u>, <u>anxiety</u>, <u>constipation</u>, low blood pressure, and many others can start at any time. Individuals who seek expert care from a comprehensive healthcare team typically have better outcomes.

#### What are the symptoms of Parkinson's disease?

Every person with Parkinson's experiences symptoms unique to them. Movement symptoms include tremors, slowness of movement, stiffness, and problems with balance and falls. There are also non-movement symptoms which include low blood pressure, anxiety, depression and problems with fine motor skills and sleep.



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#### What are the early signs of Parkinson's disease?

**Early signs** of Parkinson's include tremor, slowness of movement, trouble sleeping, a soft voice, small handwriting, loss of sense of smell, constipation, masked face, dizziness and stooped posture.

#### How is Parkinson's diagnosed?

There is no specific test to diagnose Parkinson's. A diagnosis of Parkinson's disease is often based on an in-office medical examination and neurological tests, medical

history, symptom history, medical problems, current and past medications and response to medication.

#### What is the treatment for Parkinson's disease?

Medications, <u>exercise</u>, rehabilitation therapies including physical, occupational and speech therapies, surgical options, as well as a healthy diet can help manage symptoms. People living with Parkinson's who seek expert care from a movement disorder specialist (a specialized neurologist) and comprehensive care team also have better outcomes.

#### What kind of doctors treat Parkinson's disease?

Neurologists treat Parkinson's disease. These doctors specialize in brain and nervous system disorders. Movement disorder specialists are neurologists who have completed additional training in movement disorders, a subspecialty in neurology.

#### Do people with Parkinson's face greater risks when they are hospitalized?

Research shows that three out of four people with Parkinson's do not receive medications on time when staying in the hospital. When this occurs, two out of three will experience unnecessary complications. With more frequent hospital visits and a high sensitivity to the timing and dosing of PD medications, people with Parkinson's face greater risks in the hospital. To better understand the risks associated with hospital stays; the Parkinson's Foundation has tools and resources to help you play an active role in your care. Prepare for a hospital visit — whether planned or unplanned — and

Parkinson's Foundation Aware in Care kit







establish a plan to get the safest and best possible care in the hospital, when you order or download a Parkinson's Foundation <u>Aware in Care hospitalization kit</u>.

#### How much and what types of exercise are recommended for a person with Parkinson's?

Increasing physical activity to least 2.5 hours a week can help manage Parkinson's symptoms and improve quality of life, according to the <u>Parkinson's Outcomes Project</u>, the largest-ever clinical study of Parkinson's with more than 13,000 participants. This could be walking, riding a stationary bike, treadmill or even structured exercise like boxing. Other exercises that are helpful include Tai Chi, yoga and dance — anything that is safe and gets you moving! The most appropriate exercise for a person with PD will depend on current symptoms, state of disease progression and overall physical health. Consult with your physician and a physical therapist before commencing a new exercise program.

#### Is surgery a treatment for Parkinson's disease?

There are two types of surgery for Parkinson's: <u>deep brain stimulation (DBS)</u> and the <u>Duopa pump</u>. Deep brain stimulation is a surgical procedure that involves having electrodes inserted into a targeted area of the brain. The procedure is used to help with Parkinson's symptoms such as tremors, rigidity, stiffness, and slowed movement. Duopa pump therapy is where a form of the medication carbidopa/ levodopa is delivered in gel form directly to the intestine through a tube inserted in the stomach wall. It requires surgery to deliver the medication.

#### What is a DaTscan?

A DaTscan is an imaging technology that uses small amounts of a radioactive drug to help determine how much dopamine is available in a person's brain. Doctors may use a DaTScan to help support a PD diagnosis.

#### Can Parkinson's disease cause dementia?

Dementia can be a symptom of Parkinson's disease. <u>Parkinson's disease dementia</u> can be diagnosed when a person living with PD experiences significant cognitive decline after a year or more of motor.



#### What are Lewy bodies and what is Lewy body dementia?

Lewy bodies are clumping of the protein alpha-synuclein. This protein can be found in an area of the brain stem where dopamine cells die. <u>Lewy body dementia</u> is a type of progressive dementia that leads to a decline in thinking, memory and behavior because of sticky clumps of protein that disrupt normal brain functioning.

#### What is life expectancy of Parkinson's disease?

The lifespan for those living with Parkinson's is nearly identical to those in the general population.

#### Is Parkinson's fatal?

While Parkinson's disease itself is not fatal, those living with the condition may experience serious complications from progressing symptoms, such as balance issues that lead to falls. The rate of disease progression is different for everyone.

#### Is there a cure for Parkinson's?

Currently there is no cure for Parkinson's disease. People living with the disease who seek expert care from a comprehensive healthcare team have better outcomes.

#### Should I enroll in clinical trials?

There is a lot we still do not know about Parkinson's. Research will help us learn more and lead to better treatments. One way people with PD can help doctors and researchers better understand the disease is by participating in clinical trials. Your participation in clinical trials can help to discover new Parkinson's medications and therapies; enable early access to potentially



helpful treatments not yet available; and contribute to the diversity of research participants. If you are considering participating in a clinical trial, it is important you learn about the process and why it's so important.

To learn more about Parkinson's <u>research</u> near you, ask your neurologist and visit <u>ClinicalTrials.gov</u>, a database developed by the National Institutes of Health for people with PD and their family members.

### PART 2: U.S. Department of Veterans Affairs (VA) Resources, Benefits and Eligibility, and Access to Care

### Is Parkinson's disease a service-connected condition in the VA?

Parkinson's disease (PD) and Parkinsonism are presumptive conditions for veterans who were exposed to Agent Orange and certain other toxins during military service and those veterans can apply for service-connected comp ensation. In some cases, PD and Parkinsonism in veterans can be associated with the following:



- Exposure to Agent Orange or other herbicides during military service
  - Agent Orange: VA page on eligibility and hazardous materials
  - or call the Agent Orange Helpline at 1-800-749-8387.
  - To view the list of potential exposure locations, visit the VA page on **Exposure to Agent Orange by Location**.
- Exposure to certain other chemicals, such as solvents that contaminated water at Camp Lejeune in the past
  - <u>Learn more on the VA webpage: Camp Lejeune: Past Water</u> <u>Contamination</u>.
- Gulf War veterans with moderate or severe traumatic brain injury
  - Learn more on the <u>VA webpage: VA to Expand Benefits for</u> <u>Traumatic Brain Injury</u>.
- Other exposure areas, locations, or veterans service may include: Herbicide tests and storage outside Vietnam, veterans who served in the Korean Demilitarized Zone, <u>Blue Water Navy veterans</u>, Air Force and Air Force reserve C-123 Aircraft personnel, and service related to Thailand Military Bases.

Learn more on the VA webpage <u>Exposure to Agent Orange</u> by Location and on <u>Parkinson.org</u>.



#### How can I apply for service-connected compensation?

Visit <u>https://www.va.gov/disability/how-to-file-claim/</u> for the information you need to apply. A local Veterans Service Organization can also assist you in applying for service-connected compensation.

### How do I file a VA disability claim for Parkinson's disease and find a Veterans Service Officer (VSO)?

Visit <u>https://www.va.gov/disability/get-help-filing-claim/</u> for more information on assistance filing claims, including information on VSO's and where to find them.

### If I don't have service-connected Parkinson's disease, can I still access PD-related medical care?

Yes, if you are eligible for VA healthcare benefits, you can receive care regardless of service connection.

#### Where can veterans with Parkinson's receive PD care through the VA?

The VA treats veterans with Parkinson's through the <u>Parkinson's Disease Research</u>, <u>Education & Clinical Centers (PADRECCs)</u> and <u>Consortium Centers</u> that offer care to all veterans currently enrolled in the VA Healthcare System.

Developed in 2001, the PADRECCs treat PD using state-of-the-art clinical care, education, research and national outreach and advocacy. PADRECCs are staffed by internationally known movement disorder specialists, neurosurgeons, psychiatrists, psychologists, nurses, researchers, educators, social workers and other PD experts. The six PADRECC centers are located in VA Medical Centers in:

- Philadelphia, PA
- Richmond, VA
- Houston, TX
- West Los Angeles, CA
- San Francisco, CA
- Portland, OR/Seattle, WA (both sites combined are the Northwest PADRECC)

PADRECCs also coordinate a network of <u>Consortium Centers</u> that ensure accessible and specialized PD care for veterans. There are currently 51 Consortium Centers, each offering specialized PD and movement disorder care to veterans who cannot travel to a



PADRECC. Veterans who cannot visit a PADRECC facility can be treated at their nearest Consortium Center or through telemedicine. Together, PADRECCs and Consortium Centers provide Parkinson's care within the VA system.

Learn more about PADRECCs at <u>www.parkinsons.va.gov</u> or 1-800-949-1001, ext. 205769. To check your eligibility for VA care and to apply, visit <u>www.va.gov/health-care</u>.

#### Who is eligible to receive expert Parkinson's care at a PADRECC or Consortium Center?

To be eligible for care at a VA PADRECC or Consortium Center, the veteran must already be enrolled in the VA Healthcare system.

### If I am a veteran enrolled in VA healthcare, how can I get referred to a PADRECC or Consortium Center?

First, check out the <u>Getting Care Page</u> to find a PADRECC or Consortium Center close to you.

Secondly, ask your VA primary care provider or neurologist to make a referral to the PADRECC or Consortium Center using an inter-facility consult (IFC) or you can contact the PADRECC or Consortium Center directly to self-refer for care.

Finally, call the **PADRECC/Consortium Hotline** at **1-800-949-1001 x20 5769** if you need assistance with the above process or locating a PADRECC or Consortium Center.

#### Who is eligible for VA healthcare benefits?

Veterans who served in the active military, naval, or air service and did not receive a dishonorable discharge may be eligible for VA healthcare benefits. Veterans who served in the Reserves or National Guard may also qualify for VA benefits depending on active duty status. To learn more visit: <u>https://www.va.gov/health-care/eligibility/</u>

#### What are U.S. Department of Veterans Affairs (VA) Health benefits?

VA Health Benefits covers all the necessary inpatient hospital care and outpatient services to promote, preserve or restore your health. VA medical facilities provide a wide range of services including surgery, critical care, mental health, orthopedics, pharmacy, radiology and physical therapy. The VA offers a wide array of additional health and financial benefits and services to veterans. To learn more, visit the <u>VA webpage:</u> <u>Healthcare</u>.



#### How do I apply for VA healthcare?

There are several options to apply for VA healthcare. Visit: <u>https://www.va.gov/health-</u> <u>care/how-to-apply/</u>

You can also <u>visit your local VA healthcare center</u> to sign up for healthcare benefits. At that point, if you are eligible for care, they would assign you to a primary care provider with the VA. Some veterans will have a copay for healthcare and services through the VA and some will not, based on either income or service-connected compensation. Make sure you locate your DD214 Form (a complete and thorough document that verifies a service member's proof of military service) as you will need that to register for VA Healthcare services. You can request a copy of your DD214 by visiting: <u>Request Military</u> <u>Service Records | National Archives</u>

If you are a Veteran and are not yet in the Veteran Affairs Healthcare System, <u>print your</u> <u>VA Welcome Kit</u> and explore <u>Vets.gov</u> to learn about benefits.

**Can I get help filing my claim?** You can get help in any of these ways:

- Call 800-827-1000 (TTY: 711)
- <u>Go to your nearest VA regional office</u>
- Connect with a <u>trained professional trusted to help with VA-related</u> <u>claims</u>

#### What in-home and community-based services are available through the VA?

The VA has several in-home and community-based services available to support eligible veterans and their caregivers, including Adult Day Healthcare, Home Based Primary Care, Homemaker & Home Health Aide Care, Hospice Care, Palliative Care and Respite Care. To learn more visit: <u>Home and Community Based Services - Geriatrics and</u> <u>Extended Care (va.gov)</u>

#### What resources are available to support care partners?

The <u>VA Caregiver Support Program</u> offers many services designed specifically to support caregivers of veterans including resources, education, support, and more. Support services may include one-on-one coaching, virtual support groups and web-based education and training. A caregiver can be a spouse, another family member or friend — anyone that's assisting the veteran on a regular basis.

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To learn more about the VA Caregiver Support Program visit: <u>www.caregiver.va.gov</u> or call the National Caregiver Support Line, at 1-855-260-3274. For caregiver resources through the Parkinson's Foundation, visit <u>Parkinson.org/</u> <u>caregivers</u> or call our Helpline at 1-800-4PD-INFO (473-4636).



## Do the PADRECCs have support groups/education programs available for Veterans?

Yes, each PADRECC has a support group/education program for veterans and their care partners. Groups may meet in-person or virtually. For a listing of PADRECC groups, visit: For Veterans and Family - Parkinson's Disease Research, Education and Clinical Centers (va.gov). Some Consortium Centers also offer support groups/education programs, but this varies by facility. Contact your local VA facility to find out more about their specific programs.

#### What is VA Aid and Attendance or Housebound benefits?

VA Aid and Attendance or Housebound benefits provide monthly payments added to the amount of a monthly VA pension for qualified veterans and survivors. If you need help with daily activities or you are housebound, find out if you qualify using the VA webpage: VA Aid and Attendance benefits and Housebound allowance. This can help supplement a veteran's income. There is a limit as to the yearly income and assets a veteran can have for this benefit. VA social workers can help connect you with these services and resources.

#### Is long-term care available through the VA?

Long-term care can be available through the VA. Several VA's throughout the country have what are called Community Living Centers. Those are embedded within the VA medical centers and provide long-term care services. Beds are often limited and there are eligibility criteria for admission to those facilities. In addition, VA contracts with certain nursing facilities in the community and may cover the cost for eligible veterans. For eligibility questions, contact the social worker in your local VA.





For more information about your local State Veterans Homes, talk with a VA social worker/case manager about eligibility requirements. More information can also be found at: **State Veterans Homes - Geriatrics and Extended Care (va.gov)** 

State Veterans Homes are not part of the VA healthcare system. They are owned and operated by state governments so veterans can apply whether they are enrolled in VA healthcare or not. Each state establishes eligibility and admission criteria for its specific veterans home.

#### What is the role of a VA social worker?

Social workers often act as liaisons and advocates. They help link veterans to both VA and community resources. They provide information on VA healthcare and benefits and connect people to necessary home care services to support treatment goals. They also provide counseling services to veterans and their families and caregivers.

The Parkinson's Foundation Helpline staff can also assist veterans and their families with Parkinson's-specific questions and local resources. Call our free Helpline, in either English or Spanish at 1-800-4PD-INFO (1-800-473-4636) or email us at any time at Helpline@parkinson.org

# Does the VA offer physical therapy (PT) and occupational therapy (OT) services for veterans with PD?

It is recommended that someone who is diagnosed with Parkinson's be evaluated by both a physical and occupational therapist. A PT will be able to evaluate a patient's lower extremity musculoskeletal strength, as well as their range of motion and look at their balance. An occupational therapist can help assess needed changes in your home or work environment, your approach to tasks to meet any PD-related challenges, and help you find assistive devices to live more independently.

The VA provides outpatient physical and occupational therapy at its main hospitals and may be available at some Community-Based Outpatient Clinics (CBOCs). If a patient is not close to any of these locations, they may qualify for therapy in the community through VA community care. The veteran with PD or the care partner can ask their VA primary care provider or neurologist for a referral to physical or occupational therapy.

LSVT BIG (Lee Silverman Voice Treatment, physical or occupational therapy program)

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is a specialized amplitude-based exercise program to help patients with Parkinson's and related movement disorders improve the quality and size of their movements. LSVT BIG is offered at some VA medical centers, if it is not offered it may be available via VA community care. Talk to your VA primary care provider or neurologist if interested and ask for a referral to physical therapy.



## Many people with Parkinson's experience speech and voice disorders. What type of speech therapy services are offered by the VA?

A speech-language pathologist (SLP) can evaluate speech and voice disorders and instruct exercises for strengthening vocal quality. LSVT LOUD, which is similar to LSVT BIG, focuses on the quality and amplitude of a patient's voice rather than their movements. The VA currently offers LSVT Loud therapy through some VA medical centers either in person or via telemedicine. If it is not available at your VA medical center it may be available via VA community care. Talk to your VA primary care provider or neurologist if interested and ask for a referral to speech therapy.

# What is the process for deep brain stimulation (DBS) or another Parkinson-related surgical treatment? Do I have to go to a VA facility, or can this be done by a civilian surgeon?

You need to be seen and evaluated by a VA neurologist to determine if you are an appropriate candidate for the treatment. If the treatment/surgery is not available at your local VA, you may be able to receive it by a civilian surgeon via VA community care. Contact your local PADRECC or Consortium Center to explore further: https://www.parkinsons.va.gov/care.asp.



#### FOR MORE INFORMATION:

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WWW.PARKINSONS.VA.GOV/CARE