Veterans Guide

A Resource for Veterans with Parkinson's Disease and Their Care Partners







About this guide

This guide is designed for veterans with Parkinson's disease (PD) and their care partners. It covers frequently asked questions about Parkinson's, as well as the specialized care and benefits available to many veterans through the U.S. Department of Veterans Affairs (VA).

Inside, you will find essential information about PD, tips for living well with PD, an overview of the resources, care and benefits available through the VA, and information about how to access support.

The Parkinson's Foundation is here to help. If you have any questions while reading this guide, our Helpline specialists are available to assist. Call 1-800-4PD-INFO (1-800-473-4636) or email Helpline@Parkinson.org.

For more information:

Parkinson.org/Veterans www.Parkinsons.VA.gov

Acknowledgements

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Parkinson's Foundation Resources

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What is Parkinson's disease?

Parkinson's disease (PD) 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. Movement (or motor) symptoms can include tremors, slowness of movement and problems with balance. Non-movement (or non-motor) symptoms 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.

How many people have Parkinson's disease?

There are approximately 10 million people worldwide and one million people in the U.S living with Parkinson's. Each year approximately 90,000 people in the U.S. are diagnosed with Parkinson's. There are approximately 110,000 veterans with PD who receive treatment through the U.S. Department of Veterans Affairs (VA).

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 **Young-Onset Parkinson's disease (YOPD)**.

How is Parkinson's diagnosed?

There is no specific test to diagnose Parkinson's. A <u>diagnosis</u> 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. Doctors may use a DaTscan or the Syn-One Test® to help inform a diagnosis.



Newly Diagnosed Resources

The Parkinson's Foundation has resources for people newly diagnosed with Parkinson's. The <u>Newly Diagnosed Guide</u> ensures that people with PD and their loved ones have the information they need after a diagnosis and know where to go for more when they are ready. Visit <u>Parkinson.org/NewlyDiagnosed</u>.

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 present in a person's brain.

What is a Syn-One Test®?

The Syn-One Test® is a pathological test that uses a skin sample to confirm the presence of phosphorylation in nerves, which can carry the protein that plays an essential role in Parkinson's.

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. For some veterans, developing Parkinson's can be linked to Agent Orange or other toxin exposure during military service. Refer to **Part II** to learn more.

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.

10 Early Signs Parkinson's of Parkinson's oundation **Soft or Low Voice** Tremor **Trouble Moving** Constipation or Walking Loss of Smell **Masked Face** Trouble Stooped or Hunched Over Sleeping Small **Dizziness** Handwriting or Fainting Learn more at Parkinson.org/EarlySigns

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 **gene mutations**.

<u>PD GENEration: Mapping the Future of Parkinson's Disease</u> is a national initiative that offers genetic testing for PD-related genes and genetic counseling at no cost for people with a diagnosis of Parkinson's. Learn more and enroll at <u>Parkinson.org/PDGENEration</u>.



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.

How does Parkinson's disease progress?

The rate of Parkinson's progression is unpredictable, as it is unique to every person living with the disease. The disease does advance over time. Usually movement 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. Non-movement symptoms like <u>depression</u>, <u>anxiety</u>, <u>constipation</u>, low blood pressure, and many others can start at any time.

In later PD stages, <u>balance</u> becomes a problem along with advancing symptoms interfering with activities of daily living. Individuals who seek expert care from a comprehensive healthcare team typically have better outcomes.

What is the treatment for Parkinson's disease?

Medications, exercise, rehabilitation therapies including physical, occupational and speech therapies, surgical options, as well as a healthy diet can help manage symptoms.

What kind of doctors treat Parkinson's disease?

Many types of clinicians can treat Parkinson's. Neurologists specialize in brain and nervous system disorders. Movement disorder specialists are neurologists who have had additional training in Parkinson's. Refer to <u>Part II</u> to learn about Parkinson's care available through the VA.

The Importance of Exercise

Increasing <u>physical activity</u> to least 2.5 hours a week can help manage Parkinson's symptoms and improve quality of life, according to Parkinson's Foundation research. The ideal type of exercise depends on your unique PD symptoms and challenges. Exercise can include walking, riding a stationary bike, gardening or structured PD group fitness classes, including non-contact boxing. Other exercises that can help include Tai Chi, yoga and dance — the best exercise is the one that you enjoy doing and gets you moving!

Learn more at Parkinson.org/Exercise.



What other medical professionals can help manage Parkinson's symptoms?

People living with Parkinson's benefit most from a team-based healthcare approach where a group of experienced healthcare professionals help manage PD symptoms. Your care team can include your PD doctor, speech-language pathologist, physical therapist, social worker, and nutritionist, among many other professionals.





To find a doctor in your area who is experienced in Parkinson's, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636).

Is surgery a treatment option for Parkinson's disease?

The two most common types of surgery for Parkinson's are deep brain stimulation (DBS) and the **Duopa™** therapy.

- 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™ therapy is a form of the medication carbidopa-levodopa delivered in gel form directly to the intestine through a tube inserted in the stomach wall. Surgery is required to place the tube in the intestine.

There are several other less common surgical treatments, including Focused Ultrasound.

Can Parkinson's disease cause dementia?

About half of people with Parkinson's will be affected by mild cognitive impairment changes in the memory and thinking that are noticeable, but not enough to affect daily activities. As the disease progresses, people with Parkinson's can develop more significant memory and thinking problems, sometimes called dementia.

Hospital Safety

Every year, 1 in 6 people with Parkinson's will experience avoidable complications in the hospital. People with PD are at a higher risk of being hospitalized and face many challenges while in the hospital. Careful preparation and clear communication can help minimize complications and recovery time.

The **Hospital Safety Guide** is a resource for people with Parkinson's and care partners filled with tools and information to prepare for and navigate a hospital stay. Visit Parkinson.org/HospitalSafety.



What is Lewy body dementia?

When alpha-synuclein, a protein that is central to Parkinson's, forms sticky clumps, called Lewy bodies, it can disrupt normal brain functioning and lead to dementia. Because of this, the term <u>Lewy body dementia</u> may sometimes be used and includes two different types of related dementias.

What is the life expectancy of a person living with Parkinson's disease?

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

Is Parkinson's fatal?

No. While Parkinson's itself is not fatal, those living with the disease may experience serious complications from progressing symptoms, such as balance issues that lead to falls and speech and swallowing issues that can lead to aspiration pneumonia. 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.

Getting Involved in Parkinson's Research

There is a lot we still do not know about Parkinson's. Research will help us learn more and develop better treatments. One way people with Parkinson's can help doctors and researchers better understand the disease is by participating in clinical trials.

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



Many U.S. veterans with Parkinson's disease (PD) have access to specialized medical care and financial assistance through the U.S. Department of Veterans Affairs (VA). Since 2020, the VA and the Parkinson's Foundation have formally partnered to improve the health, well-being, and quality of life for veterans living with Parkinson's.

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

Parkinson's disease and Parkinsonism are presumptive conditions for veterans who were exposed to Agent Orange and certain other toxins during military service. Those veterans can apply for VA disability compensation.

In some cases, PD and Parkinsonism can be associated with the following:

- Exposure to Agent Orange or other herbicides during military service
 - To learn more visit the VA webpage on <u>eligibility and hazardous materials</u> or call the Agent Orange Helpline at 1-800-749-8387.
 - To view the list of potential exposure locations, visit: <u>Exposure to Agent Orange</u> <u>by Location</u>.
 - The PACT Act of 2022 added several locations to the areas eligible for Agent Orange presumptions, including Thailand, Cambodia, Laos, Guam, American Samoa and Johnston Atoll. To learn more visit the VA webpage on the <u>PACT Act</u>.
- Exposure to contaminants in the water supply at Camp Lejeune from the 1950s through the 1980s (Note: Only Parkinson's disease is a presumptive service-connected condition for those exposed at Camp Lejune, not Parkinsonism.)
 - o To learn more, visit: <u>Camp Lejeune: Past Water Contamination</u>.
- Gulf War veterans with moderate or severe traumatic brain injury
 - To learn more, visit **VA to Expand Benefits for Traumatic Brain Injury**.



 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 **Exposure to Agent Orange** and on **Parkinson.org/Veterans**.



Veterans and their families can call 1-800-MyVA411 (1-800-698-2411), a single access point to all VA contact centers. The number is available 24 hours a day, 365 days a year to serve Veterans, their families, caregivers and survivors.

How can I apply for VA disability compensation?

Visit <u>How to File a VA Disability Claim</u> for the information you need to apply. A local Veterans Service Organization (VSO) can also help you apply for VA disability compensation.

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

Visit <u>Get Help Filing a Claim</u> for more information on assistance filing claims, including information on VSO's and where to find them. You can get help through:

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

If I don't have a VA disability rating for PD, can I still access PD-related medical care?

Yes. If you are eligible for VA healthcare benefits you can receive care, regardless of whether you have a VA disability rating for PD.

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, Education</u> & <u>Clinical Centers (PADRECCs)</u> and <u>PADRECC Associated Sites</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 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>Associated Sites</u> that ensure accessible and specialized PD care for veterans. There are currently more than 60 Associated Sites, each offering specialized PD and movement disorder care to veterans who cannot travel to a PADRECC. Together, PADRECCs and Associated Sites 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>.

Telemedicine

Veterans who cannot travel to a PADRECC facility can be treated through telemedicine. Ask either your VA primary care provider or your VA neurologist to make a referral for a Video Visit with your nearest PADRECC or Associated Site using an inter-facility consult (IFC). Learn more at Getting Care.

Who is eligible to receive expert Parkinson's care at a PADRECC or Associated Site?

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

If I am a veteran enrolled in VA healthcare, how can I get a referral to a PADRECC or Associated Site?

- 1. Visit the **Getting Care** webpage to find a PADRECC or Associated Site near you.
- Ask your VA primary care provider or neurologist to make a referral to the PADRECC or Associated Site using an inter-facility consult (IFC). If you cannot visit a PADRECC facility or Associated Site, ask for a referral for a Video Visit with your closest PADRECC or Associated Site.



3. Call the **PADRECC Network Hotline** at **1-800-949-1001 x20 5769** if you need assistance with the above process or locating a PADRECC or Associated Site.

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: **Eligibility for VA Health Care**.

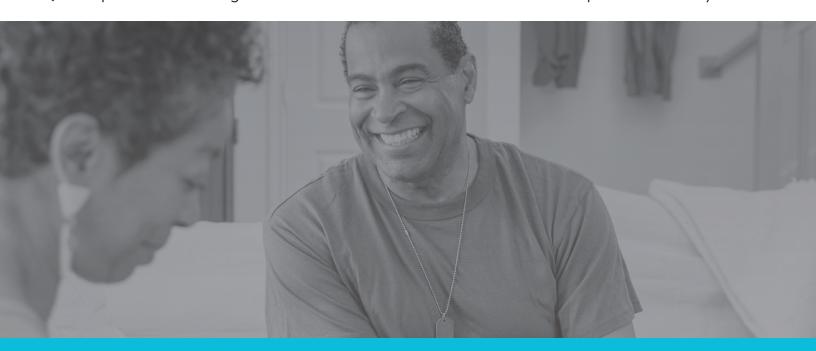
What are U.S. Department of Veterans Affairs (VA) Health benefits?

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 eligible veterans. To learn more, visit: Health Benefits.

How do I apply for VA healthcare?

There are several options to apply for VA healthcare. To learn more, visit: <u>How to Apply for VA</u> Healthcare.

To sign up for healthcare benefits visit your <u>local VA healthcare center</u>. 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 connection rating. 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. To request a copy of your DD214 visit Request Military Service Records.

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

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: Home and Community Based Services - Geriatrics and Extended Care.

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, family member or friend — anyone that's assisting the veteran on a regular basis.

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/Caregivers</u> or call our Helpline at 1-800-4PD-INFO (1-800-473-4636).

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. Some PADRECC Associated Sites also offer support groups/education programs, which varies by facility. Contact your local VA facility to learn about their specific programs.



Mental Health

Symptoms related to mental health like depression and anxiety are common in PD. They can be the result of living with a chronic condition, but they can also be a symptom of the disease itself and changes in the brain. Be aware of these symptoms and do not hesitate to talk to your doctor. Keep the Veterans Crisis Line number nearby — dial 988 then press 1 or text 838255.

What is VA Pension, Aid and Attendance or Housebound benefits?

- <u>VA Pension</u> provides monthly payment to wartime Veterans who meet certain age or disability requirements and who have income and net worth within certain limits.
- VA Aid and Attendance or Housebound benefits provide monthly payments added to the amount of a monthly VA pensions for qualified Veterans and survivors. You may qualify if you need help with daily activities or you are housebound. 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 and Veteran Service Officers (VSOs) 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 VAs throughout the country have Community Living Centers, which 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. Learn more at: State Veterans Homes.

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 veteran's home.



What is the role of a VA social worker?

Social workers often act as liaisons and advocates. They can:

- Help link veterans to VA and community resources.
- Provide information on VA healthcare and benefits
- Connect people to necessary home care services to support treatment goals.
- 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 lower extremity musculoskeletal strength, as well as range of motion and 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 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 veteran is not close to any of these locations, they may qualify for therapy in the community through <u>VA Community Care</u>. Veterans 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) 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. Does the VA offer speech therapy services?

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 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?

A VA neurologist must complete an evaluation to determine if you are a 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 Associated Site to explore further.



About the Parkinson's Foundation

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure.

In everything we do, we build on the energy, experience and passion of our global Parkinson's community. Information about Parkinson's and resources are available at Parkinson.org.

Your generosity makes this publication possible.

The Parkinson's Foundation is proud to provide this guide and other educational materials at no cost to people around the world. If you found this resource helpful, please consider a donation to help us continue to offer up-to-date, high quality educational materials about Parkinson's, as well as fund innovative research and support services.

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