

What Do I Need to Know?



Some Facts

What are PD and Parkinsonism?

Parkinson's disease (PD) is a chronic, neurological disease, commonly referred to as a *movement disorder*. It is caused by a loss of dopamine producing cells in the brain. Classic *motor* symptoms, also called the "cardinal features" of PD, include tremor during rest, stiff limbs, slowness of movement, gait and balance problems that progress over time. *Non-motor* symptoms, such as sleep disturbances, urinary dysfunction, constipation, swallowing problems, mood disorders and cognitive deficits, can occur as well. "Parkinsonism" is the generic term used to refer to slowness and mobility problems that include PD and atypical parkinsonian disorders. Atypical disorders are also called "parkinson plus" syndromes and include Lewy body disease (LBD), progressive supranuclear palsy (PSP), multiple system atrophy (MSA) and corticobasal degeneration (CBD). The atypical disorders are more aggressive diseases and tend to progress quicker than PD.

Treatment may include:

Medication, exercise, and self care are the cornerstones of treatment for PD. Unfortunately there is no cure for PD yet, and no medications have been found to slow the progression of the disease. But there are many

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Physical and Mental Changes to Expect

Parkinson's disease (PD) is a chronic and complex neurological disease, not an acute illness. Symptoms of PD vary widely and disease progression can vary considerably from one person to another. But for most people, PD presents as a slow, progressive illness and persons with PD often live an average lifespan. PD is typically thought of as a movement (motor) disorder with symptoms of slowness, stiffness and tremor. However, a number of non-motor symptoms commonly occur as well, and may appear before the motor impairments. Non-motor symptoms can cause problems with thinking, depression and anxiety, loss of smell, vision changes, constipation and sleep disturbances. These non-motor symptoms are important to quality of life and are often more bothersome than the motor symptoms. It is important to talk to the health care team about all symptoms so they can be addressed properly. Symptoms can be controlled by medication and other therapies. However, in the advanced stages of the disease, symptoms such as increased falls and impaired thought processes may become serious enough to warrant in-home support services or long-term care placement such as an assisted living facility or nursing home.

Physical changes may include: Tremor; slowness of movement; stiffness of the arms, legs or trunk; balance problems; freezing of gait; small, cramped handwriting; reduced arm swing; loss of facial expression; softness of voice; tendency to fall backwards; walking with a series of quick, small steps; constipation; erectile dysfunction; bladder control problems; drooling; sleep problems; loss of sense of smell; vision changes; and restless leg syndrome.

Mental changes may include: Difficulty with attention, focus, planning, multitasking; visual spatial functions (driving); apathy or lack of motivation; hallucinations (seeing things that aren't really there) and/or delusions (believing things that aren't true); impulsive behavior (gambling, shopping, eating, sexual behaviors); problems with memory.

Emotional changes may include: Anxiety and depression.

What Does This Mean for Me?

It is possible to live well with PD despite the physical and/or cognitive changes that come with the disease progression. PD is often considered a family disease because of the effect it may have on the person's family and friends. Being a Caregiver is an important role and most often performed by the spouse, or an adult child. In the early and middle stages of the disease, the role is often described as a partnership. The care partner and the person with PD have a dynamic relationship as both adjust to sharing duties and working together. In the later stages of the disease, caring for someone with PD may become physically and emotionally draining. It is important for Caregivers to remember that it is okay to ask for help, and to acknowledge that one person cannot do it alone. Caregivers often feel empowered and supported by staying engaged in social activities, building a strong backup team, and attending support groups.

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effective medications that can reduce symptoms, along with rehabilitation therapies (physical, speech, occupational) and a surgical treatment called deep brain stimulation surgery (DBS). Timing of medications is critical to symptom control along with daily exercise, good nutrition and stress management. Treatment for this disease requires an interdisciplinary team approach that includes medicine, nursing, rehabilitation, psychology and social work. In advanced disease, treatment should include palliative care, hospice or end of life care.

More information:

Check VA's Parkinson's Disease Research Education and Clinical Center (PADRECC) website www.parkinsons.va.gov for information under the section "For Veterans and Families."

American Parkinson Disease Association (APDA)
www.apdaparkinson.org

Michael J. Fox Foundation for Parkinson's Research
www.michaeljfox.org

National Parkinson Foundation
www.parkinson.org

Parkinson's Disease Foundation (PDF)
www.pdf.org

Caregiving Tips

1. **Educate yourself and find a good doctor:** Keep up to date on your loved one's disease and do not be afraid to ask questions at doctor visits. Being educated helps you better understand what is happening to your loved one. Always bring an updated list of medications to all doctor appointments. Consider finding a neurologist who specializes in movement disorder.
2. **Hospitalization and PD:** Being hospitalized can be stressful for both the Veteran with PD and his/her Caregiver. Often, it becomes the Caregiver's responsibility to educate hospital staff on the importance of the medication schedule and ensuring the Veteran is receiving his/her medications on time, as they may not be knowledgeable about PD management and treatment. Contact the Veteran's movement disorder specialist or treating neurologist to make them aware of the hospitalization and ask him/her to contact the hospital neurologist to discuss the treatment plan.
3. **Take care of yourself:** Address your own medical needs, eat well, exercise, sleep and take time for yourself. It is important to maintain your health so you can continue to provide the best care for the Veteran. Do not allow the disease to become you or the center of your life. Maintain a healthy social life and hobbies you had before you became a Caregiver.
4. **Be realistic and access help:** Know what you can do and recognize when you have given all that you can. Access community resources such as home health care, respite, adult day health care, nursing home, etc. If family members or friends offer to help, let them, and be specific in ways they can help.
5. **Depression:** Be aware of the signs and symptoms of depression for both you and the Veteran and do not delay in seeking support or professional counseling. Keep contact information for a psychiatrist/therapist, Veteran's Crisis Line (1-800-273-8255) and other emergency phone numbers handy.
6. **Breathe/meditate:** Try yoga, tai chi and/or deep breathing. These exercises will help slow your heart rate and calm your emotional state which, in turn, will help you think more clearly and feel refreshed.
7. **Emotional support:** Consider attending a support group where you can share your concerns and feelings and talk with other Caregivers. This can help reduce any feelings of being alone. Support groups offer mutual support as well as valuable information on PD.
8. **Positive thinking and humor:** Think "I can do this!" Laughing is a great stress reliever.
9. **Long term care planning:** It is important to explore future plans such as advance directives, living wills and care at home versus nursing home placement, etc. Be sure to discuss these issues and decisions with loved ones to ensure the Veteran's wishes are followed.



I have more questions. Where can I go for help?

VA knows that being a Caregiver can be both rewarding and hard. You can always find more information at www.caregiver.va.gov, including contact information for the VA Caregiver Support Coordinator near you.

You can also call VA's Caregiver Support Line
toll-free at 1-855-260-3274.

The Caregiver Support Line is open
Monday through Friday, 8:00 am – 11:00 pm ET,
and Saturday, 10:30 am – 6:00 pm ET.

Call to talk to caring professionals who can:

- Tell you about assistance available from VA.
- Help you access services and benefits.
- Connect you with your local Caregiver Support Coordinator at a VA Medical Center near you.
- Just listen, if that's what you need right now.