

Parkinson's Disease Tip Sheet

What is Parkinson's disease (PD)?

Parkinson's disease is a progressive neurological condition where brain cells that create a substance called dopamine gradually change and lose function. Dopamine is important for coordination of activity throughout the body. Because symptoms may develop slowly, some years may pass before diagnosis is established. PD is a progressive disease, and there is no cure. However, there are a significant number of medications to manage the symptoms. The "gold standard" for treatment is a medication called levodopa that helps replace the lost dopamine in the brain. With long term levodopa treatment over a number of years, patients can develop dyskinesias, uncontrolled flailing movements of the head, arms, legs and body. Sometimes the medication may not work, and the patient will be in an "off" period, as opposed to when his medication is working and he is "on". Also, the patient may have "end of dose" fluctuations in ability to daily tasks as the medication wears of. Newly approved drugs are widening the choice of therapies, and surgical procedures—such as deep brain stimulation (DBS)—are helpful for appropriate candidates. Exercise is also very important to the overall health and wellness of those with PD.

What are the symptoms of PD?

Four major symptoms: *Individuals may have some of these symptoms or all of them.

- 1. Slowness of movement and difficulty initiating movement
- 2. Tremor at rest
- 3. Rigidity (stiffness of muscles)
- 4. Postural changes (stooped posture, shuffling and balance difficulties

Other possible symptoms include: depression; emotional changes; difficulty with swallowing and chewing; speech changes (quiet voice); urinary problems/constipation; skin problems; sleep problems; dementia/cognitive problems; orthostatic hypotension (sudden drop in blood pressure when standing up); muscle cramps; pain; fatigue; loss of smell; tiny writing; sexual dysfunction

What causes PD?

The cause(s) of PD is still unknown but among the possibilities under consideration are genetic predisposition, exposure to environmental toxins and a combination of the two.

More Information:

For more information on PD, local resources, a list of area neurologists and area support groups, contact Lynne Gotham, Executive Director of the Parkinson Partners of NW PA, Inc. at 814-899-3030

Working with an Individual with PD

- *Always give PD medications on time and at regularly scheduled intervals. Be consistent. Many people need to take their medication one half to one hour before meals or two hours after meals to get the best benefit from the medications. Follow the neurologist's orders strictly about timing medications around meals.
- *Keep track of which PD symptoms appear and how soon they reappear after each dose of medicine so this can be reported to the neurologist. This information is an important tool for the doctor to adjust the medicines to best manage the disease.
- *Do not assume that a PD patient is not listening to you if their face remains expressionless and unresponsive. A "flat face" or "mask-like face" can be a part of the disease.
- *Do not assume that a PD patient is being uncooperative or is not listening to you, if they are slow to follow instructions or to start an activity. This slowness of thought process and action is part of the disease.
- *<u>Do not tell a PD patient to hurry.</u> Slowness is part of the disease and telling them to hurry will just make it worse.
- *Because of the varying effect of medication, the PD patient may not be consistent in their ability. When the medication is working they may be able to feed themselves. However they may be unable to feed themselves at the next meal. They are not being uncooperative. This is part of the disease. They may be able to do a lot of activities when their medication is working, and they are "on", but may be unable to do those very same things when their medication is not working, and they are "off".
- *Plan all important activities (eating, outings, social events) for when the patient is "on" and their medication is controlling symptoms.
- *If the medication is not working and the patient becomes stuck or "freezes", here are some options to try:
 - 1. Shift weight from side to side and say, "1, 2, 3 go".
 - 2. March in place and say, "left-right, left-right, let's go, left-right".
 - 3. Drop a tissue on the floor and ask the person to step over it.
 - 4. Ask the person to step over an imaginary line you draw in front of them with your foot.
 - 5. Lightly touch their hand or arm and say, "Come with me".
 - 6. Ask the person to calculate the number of steps to an object across the room and as you begin to step forward say, "Let's count the steps together—let's go, 1, 2, 3, etc."
 - 7. Take the person by the arms as though you are going to dance, and ask them to dance with you across the room to the chair.
- *The stress of living with Parkinson's disease and changes in brain chemistry can create depression. Discuss any changes in the patient's function, personality and attitudes with the doctor. Help for depression is available through medications, exercise, remaining physically active, counseling and support.
- *Remember: having Parkinson's disease is like moving through a jar of molasses...be patient and understanding.

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