

Ask the Doctor



In this section, Dr. Lauren Seeberger, M.D., answers your questions about Parkinson's disease.

Dr. Seeberger is Medical Director of the newly opened Movement Disorders Center at the Idaho Elks Rehabilitation Hospital. A nationally recognized, fellowship-trained neurologist with 15 years of experience in the diagnosis and treatment of movement disorders, Dr. Seeberger has been active in research, publication and teaching throughout her career.

There is a movement now toward treating people with PD with medications other than levodopa before they have functional disability. Do you start with some of these other medications before functional disability?

I sure do. I think you are seeing a movement toward earlier treatment among specialists, and that springs out of several areas of research in patients with early

PD. Findings in clinical trials, as well as new developments that led to the Braak Pathology Staging System [see "What Exactly Is Parkinson's Disease?" in this issue], along with brain imaging studies, make us more acutely aware of the fact that brain changes in PD begin much earlier than we originally thought. The onset of real decline in motor functions just signals the tip of the iceberg (to borrow from Dr. Langston's work).

If we can find medications with low side effect profiles, and if we know that early treatment will not lead to worsened motor complications as we see with levodopa, it's easier to make a decision to treat. We know many patients will have motor complications from therapy that may be delayed if they started on another type of agent. Now that we have the MAO-B inhibitors and the dopamine agonists, there's often no real reason to hold off treatment until functional impairment and, in fact, we may do our patients a disservice to do so.

The Balancing Act | How do others living with PD learn to cope? Hear it in their own words.

Paul and Carolyn Zeiger discuss Paul's diagnosis two years ago

Carolyn: Paul was diagnosed two years ago, but it was evident to me that he had Parkinson's long before that. I could see changes in his face—"masking," lack of movement in the neck—and there were more subtle signs, such as anxiety over small things, lethargy, and fatigue. One day I looked at him and said, "I know what it is—it's Parkinson's."

Paul: One day, while doing yoga, I couldn't kick up into a handstand against the wall, and that really got my attention.

Carolyn: That's when we got him to a neurologist. By the time he was diagnosed, he had all the basic motor symptoms: shuffling of feet, his right arm didn't swing, and he had trouble with balance when he turned.

Paul: Some recent evidence has revealed that some of these autonomic symptoms do in fact appear first; we just don't notice them because many are the same as difficulties that occur with aging. We tend not to notice that there is a pattern, with a bunch occurring at once as signs of PD.

Carolyn: The doctor wanted to wait three months and see how he was doing. Paul increased his yoga practice, and I started doing a Japanese therapy called Jin Shin Jyutsu, which involves the release of energy blocks. We did this safely every day for hours, went back to the doctor after three months, and she couldn't believe he was the same person. He got his handstand back, and his symptoms were so reduced that the doctor said he didn't need medication yet—and he is still not taking L-dopa.

Paul: Now I'm taking an MAO-B inhibitor and a dopamine agonist—but not L-dopa.

Paul and Carolyn Zeiger, Denver, Colorado

These statements are the opinions of the interview subjects and do not necessarily reflect those of Teva Neuroscience, Inc.

Life in BALANCE

A NEWSLETTER FOR PEOPLE AND FAMILIES LIVING WITH PD®



What Exactly Is Parkinson's Disease?

A New View Emerges.

Researchers agree that, in people living with PD, the nerve cells that produce dopamine are damaged and eventually lost. However, the remaining neurons try to "pick up the slack" by increasing the rate at which they make and release dopamine.

That's why the characteristic motor symptoms of PD appear only when 60% to 80% of the dopamine-producing neurons are lost.

During the last decades, many researchers began to ask why so many of the symptoms seen in people living with PD had nothing to do with movement. These are called *nonmotor symptoms*. Researchers also noticed that many people who experienced these nonmotor symptoms eventually developed PD, sometimes years later. What are these nonmotor symptoms, and what is their relationship to PD? First, let's take a look back...



"Parkinsonism" is just one part of Parkinson's disease. The characteristic motor symptoms of PD—resting tremor, slowness of movement, and stiffness—are often called "parkinsonism" or "parkinsonian symptoms." This is in honor of James Parkinson, who first carefully described PD in an essay written in 1817.

However, since that time, disorders that share some or all of these *parkinsonian symptoms*, but which are distinguishable from PD, have been found. Disorders that may cause "parkinsonism" can be caused by certain medications, toxins (such as pesticides), stroke (blockage of blood vessels in the brain), infections, inherited neurological diseases, or the "atypical parkinsonisms," a group of disorders that may closely resemble PD, but which do not respond well to treatment.

So researchers had a mystery on their hands. They wondered why "parkinsonism" seemed to be just one part of PD...why it often appeared *after* other symptoms... and why years could separate these early symptoms from "parkinsonism."

Continued on page 2

TABLE OF CONTENTS

What Exactly Is Parkinson's Disease? A New View Emerges	1
Caregiver Corner:	
Navigating the Healthcare Maze	3
Ask the Doctor	4
The Balancing Act: Reacting to the Diagnosis	4

Sorting out the mystery.

About five years ago, a researcher named Heiko Braak put together a staging system for PD that tied together many of these observations. His system has led to some controversy, a great deal of research, and an entirely new way of looking at PD.

According to Braak, damage to the dopamine-producing nerve cells of the brain causes the characteristic symptoms of PD, but PD does not *begin* in these cells. Rather, it begins long before that, in the *vagal nerve*—the main neural “highway” that ties together the brain with nerves throughout the body, including those that control the digestive system. This is Stage 1 in Braak's 6-stage system.

In fact, constipation and digestive trouble could be some of the very earliest signs of PD and occur in some people as long as 15 years before they are even diagnosed. We now know that many people have non-parkinsonian signs of PD for years, or even decades, before tremor, stiffness, or slowness of movement brings them to the neurologist.

The traditional features of PD become noticeable in Braak Stage 3 or 4, when the dopamine-producing nerve cells are affected. In Stages 5 and 6, emotional difficulties, apathy, and memory loss can occur as the disease moves into higher levels of the brain. These symptoms may not occur until many years, or even decades, after the initial diagnosis of PD is made.

Parkinsonism—just the tip of the iceberg?

Braak has called on physicians to

**OTHER SIGNS AND SYMPTOMS OF PD THAT ARE NOT PART OF THE TEXTBOOK DEFINITION MAY INCLUDE:****Rapid Eye Movement Sleep Behavioral Disorder (RBD)**

This disorder is characterized by bursts of physical activity during the night. Nearly 40% of men diagnosed with RBD eventually developed PD in one study, with an average of 13 years between the beginning of RBD and the diagnosis of PD. If you or a loved one has RBD, talk with your doctor—some medications have been shown to be effective in controlling this disorder.

Loss or decline of sense of smell

Many people living with PD state that they had a decreased sense of smell long before diagnosis.

Excessive Daytime Sleepiness (EDS)

EDS—including long naps during the day, insomnia, grogginess for more than 30 minutes after waking up, and awakening frequently during the night—is associated with a greater risk for the later development of PD. Because EDS can be caused by many medications for PD, you should talk with your doctor.

Pain in the shoulder, or tingling sensations in the limbs

Pain, stabbing, burning or tingling sensations can precede the motor symptoms of PD, often by years. A number of medications may be helpful for this sort of pain. Talk with your doctor about what you can do. There are different types of pain associated with PD, and proper treatment depends on the reason for the pain.

Depression or anxiety

Depression in people with PD is often unrecognized and undertreated. Many medications are effective in relieving depression, and psychotherapy may be effective as well. Anxiety, like depression, can develop years before the motor symptoms of PD. And like depression, there are many effective treatments—but talk with your doctor, because some anti-anxiety medications should not be used to treat people with PD.

help—and not to allow people who may be in the very earliest stages of PD to suffer from problems that may be dismissed as “daily discomforts within tolerable limits” or inevitable consequences of aging.

As Dr. William Langston says, “Parkinsonism is just the tip of the iceberg.” He means that we have to

broaden our focus so that we can (1) better help people living with PD deal with the nonmotor symptoms of PD, and (2) understand the true underlying causes of PD so that we can find more effective ways to treat it.

**MANAGING** the Healthcare System: STRATEGIES FOR SUCCESS

When someone you care about is living with Parkinson's disease (PD), the last thing you need is the frustration of dealing with the healthcare system and getting tangled in red tape. By adopting a few simple techniques, though, you can achieve the best possible care for your loved one.

Your first tool is information.

Find out exactly what type of medical coverage your loved one has, and ask the following questions:

1. What are copayments and coinsurance?

Copayments are set amounts that you pay for a service—for example, \$20 for a doctor visit or \$30 for an emergency room visit. Coinsurance is a percentage of the total bill.

2. What is your deductible?

A deductible is a set amount of money you have to pay each year before you can take advantage of your healthcare policy's benefits. It can be anywhere from hundreds to thousands of dollars.

3. If your loved one has Medicare, know what type they have.

Part A, which is sometimes called “Hospital Insurance,” primarily covers inpatient care in hospitals. Eligible people may sign up for Medicare Part B, sometimes called “Medical Insurance,” which helps cover medically necessary services such as doctor visits and outpatient care.

To get drug coverage, you must join one of the Medicare drug plans, which are run by insurance companies approved by Medicare. These Part D plans vary in the specific medications they cover, the

monthly premiums, yearly deductibles, and copayments or coinsurance. Many pharmacy chains offer information on choosing the right Part D plan for you.

For comprehensive information, visit www.Medicare.gov, the official U.S. government site. For a website that makes Medicare information easier to understand, check out the Medicare Rights Center at www.medicarerights.org.

People power

Another vital (and often overlooked) component of managing the healthcare system is developing relationships with those who can help you. Get to know the people at doctor's offices—the staff members send authorizations and referrals, and their cooperation can make dealing with insurance companies much easier.

See if you can arrange to have a single “case manager” at your insurance company. Often, a case manager will take a personal interest in your loved one's situation, and he or she can answer questions and act as an advocate if necessary. Navigating the healthcare maze may take persistence, but in the end both you and your loved one stand to gain a great deal.

In preparing this newsletter, we referred to the following sources, some of which you may find helpful.

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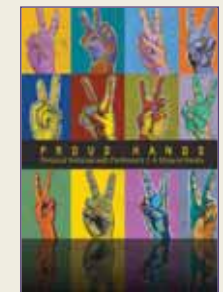
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