

# Understanding Parkinson's Secrets, Myths & Misconceptions



There are many pervasive myths and misconceptions about Parkinson's disease (PD) and its treatment. Below are some tips to help you distinguish between fact and fiction so that you can optimize both your care and your quality of life.

## Myth/Misconception

*PD only affects movement.* Most people — including some physicians — believe that PD only causes movement-related (motor) symptoms such as tremor, stiffness and slowness.

## Reality

Many symptoms of PD are unrelated to movement. Nonmotor (“invisible symptoms”) of PD are common, and may affect everyday life more than the more obvious movement difficulties. These symptoms may include impaired sense of smell, sleep disorders, cognitive symptoms, constipation, bladder symptoms, sweating, sexual dysfunction, fatigue, pain (particularly in a limb), tingling, lightheadedness, anxiety and depression.

## Secret

Good news: many nonmotor symptoms of PD are highly treatable. For this reason, you should write down your invisible symptoms, discuss them with your doctors, and seek treatment.

## Myth/Misconception

*If someone with Parkinson's looks good, then they also feel good.* People will often assume that if someone with PD looks good at one point in time, then they feel well all of the time.

## Reality

PD symptoms fluctuate, and not all of them are visible. Over time, people with PD notice an increasing tendency for their medications to wear off between doses. For this reason, the way that they appear at one moment in time may not reflect the way that they feel most of the time. Even when

someone with Parkinson's looks good, they may not feel well because of nonmotor symptoms.

## Secret

Keeping a symptom diary can help. If your symptoms fluctuate during the day, then you should keep track of your pattern of “on” times (when medications work effectively) and “off” times (when medications wear off). This will enable your doctor to optimize your medications, and help you to feel more in control of your PD.

## Myth/Misconception

*You can blame PD for everything.* It is easy for you — and for your doctors — to blame PD every time that you are not feeling well.

## Reality

Certain symptoms should never be attributed to PD. Fever, for example, is not a symptom of PD, and usually indicates an infection. Headache, vision loss, vertigo, loss of sensation, loss of muscle strength and chest pain are not symptoms of PD.

## Secret

Your doctor should rule out other causes for your symptoms. Sudden-onset symptoms — such as chest pain, shortness of breath, weakness, difficulty with speech, or vertigo — warrant immediate medical attention to rule out an emergency.

## Myth/Misconception

*PD has spontaneous “exacerbations.”* Another common assumption is that PD can “flare up” unexpectedly. But PD does not work this way. Although symptoms may fluctuate throughout the

*(over please)*



day, the progression of PD is very slow.

### Reality

If PD symptoms worsen over days or weeks, then it is critical to search for an underlying cause. Medication changes, infection, dehydration, sleep deprivation, recent surgery, stress, or other medical problems can worsen PD symptoms. Urinary tract infections (even without bladder symptoms) are a particularly common cause.

### Secret

Certain medications can worsen PD symptoms. These include antipsychotics, valproic acid (Depakote®), lithium, and nausea medications such as prochlorperazine (Compazine®), metoclopramide (Reglan®), and promethazine (Phenergan®). Speak with your neurologist before starting one of these medications, to see if there is a better alternative.

### Myth/Misconception

*Levodopa stops working after five years.* This is perhaps the single most pervasive myth about PD treatment. Many people are reluctant to start taking levodopa because of fear of “using it up.” Some physicians also share this “levodopa phobia.”

### Reality

Levodopa works for decades. Levodopa does not treat all of the symptoms of PD, but it dramatically helps many of the most disabling motor symptoms.

### Secret

Levodopa has been shown to increase lifespan and markedly improve quality of life.

### Myth/Misconception

*You should wait as long as possible to take the next dose of levodopa.* Many people feel that they should wait until their medication has completely worn off before taking the next dose.

### Reality

Levodopa is most effective when taken on time, just before the previous dose wears off. If you wait too long, then the next dose may never “kick in,” and the medications may not work effectively for the rest of the day.

### Secret

A medication timer can help. If you are experiencing wearing off of medications, then it is critical to take your doses exactly on time.

### Myth/Misconception

*Different generic brands of carbidopa/levodopa are usually different colors.*

### Reality

The color of carbidopa/levodopa tablets is relatively consistent between brands. If the color of your tablets changes for no apparent reason, then it is important to verify that you are still receiving the correct dosage.

### Secret

The most commonly prescribed dosage of carbidopa/levodopa — 25/100 mg immediate-release tablets — is always yellow in color, regardless of the brand. If you are supposed to take this dose, and your pills are not yellow, then an error has occurred.

### Myth/Misconception

*Your doctor can predict your future.* Many people with PD ask their doctor to predict their prognosis.

### Reality

PD is highly variable from person to person. Even a PD expert has no way of knowing what the future holds for an individual with PD.

### Secret

You can help to change your future. You can improve your disease at every stage by ensuring that you stay fit and receive adequate sleep and proper nutrition. Exercise is particularly important for improving mobility, stamina, mood and quality of life.

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The list was first presented by Dr. Nirenberg at a *PD Expert Briefing* in 2009. Watch the full seminar online at [www.pdf.org/expertbriefings](http://www.pdf.org/expertbriefings).

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice.

This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.