

Myths about Parkinson's

We have gathered the facts on the myths and misconceptions about Parkinson's disease (PD) and its treatment. Below are tips to help you distinguish between fact and fiction and optimize your care and quality of life.

Myth

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. Non-motor ("invisible symptoms") of PD are common, and may affect everyday life more than the more obvious movement difficulties. These 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.

TIP: Good news: many non-motor symptoms of PD are highly treatable. Write down your invisible symptoms, discuss them with your doctors, and seek treatment.

Myth

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 will always feel well.

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 may not reflect the way that they feel most of the time. Also, they may not feel well because of non-motor symptoms.

TIP: Keep a symptom diary. If your symptoms fluctuate during the day, then you should keep track of your pattern of "on" times (when your medications work effectively) and "off" times (when medications wear off). This enables your doctor to optimize your medications and help you feel more in control.

Myth

You can blame PD for everything. It is easy for you - and for your doctors - to blame PD every time 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.

TIP: Your doctors 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

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 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.

TIP: 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

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 the symptoms of PD, but it dramatically helps the most disabling motor symptoms.

TIP: Levodopa has been shown to improve quality of life.

Myth

You should postpone taking 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.

TIP: A medication timer can help. It is critical to take your doses exactly on time.

Myth

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.

TIP: The most commonly described 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, an error has occurred.

Myth

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.

TIP: 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.