Understanding Parkinson’s disease: Misconceptions, Reality and Facts

There are many myths and misconceptions about Parkinson’s disease (PD) and its treatment. Knowing what is fact or fiction can help optimize your care and quality of life.

Misconception: Parkinson’s ONLY affects movement, or motor symptoms like tremor, stiffness and slowness.

- **Reality**: Many symptoms of PD are unrelated to movement. Non-motor symptoms are quite common and include impaired sleep, constipation, bladder symptoms, fatigue, pain, tingling, lightheadedness, cognitive difficulty, anxiety and depression.
- **Fact**: Many motor and non-motor symptoms of Parkinson’s are highly treatable.

Misconception: You can judge how severe a person’s Parkinson’s is based on a single observation.

- **Reality**: Many Parkinson’s symptoms can fluctuate and not all symptoms are visible.
- **Fact**: Many people with Parkinson’s can experience ON times (when they feel well and medications are working) and OFF times (when symptoms are problematic and medications are not working). Keeping track of your symptoms in relation to your medication times and dosages can help your provider optimize your medication schedule.

Misconception: Levodopa stops working after a couple of years, so you should wait to start taking it.

- **Reality**: Levodopa works for decades, treating many, but not all symptoms of PD.
- **Fact**: Levodopa is an effective treatment for Parkinson’s and noticeably improves quality of life.

Misconception: Your doctor can predict your future and prognosis.

- **Reality**: No person experiences the same Parkinson’s progression, symptoms or reaction to treatments, so even the best doctors cannot tell you exactly what lies ahead.
- **Fact**: You can help change your future! Improve your disease at every stage by ensuring you stay fit and receive adequate sleep and nutrition. Exercise can improve mobility, stamina, mood and quality of life. People living with PD who seek expert care from a comprehensive team have better outcomes. Their complication risks are lower, and they enjoy better quality and longer lives. In fact, neurologist care saves about 4,600 lives each year in the U.S. alone.

Misconception: People experience Parkinson’s “flare-ups.”

- **Reality**: Parkinson’s symptoms do not often suddenly worsen over days or weeks, if they do, it is critical to find the underlying cause with your healthcare team. Medication changes, infection, dehydration, sleep deprivation, stress, grief and other medical conditions can greatly impact and worsen PD symptoms.
- **Fact**: Certain medications (prochlorperazine, metaclopramide, valproic acid and others) can worsen PD symptoms. Often, when infection and underlying medical or psychological issues are treated, PD symptoms improve.

Still have questions? Call the Parkinson’s Foundation Helpline at 1-800-4PD-INFO (473-4636), to speak to a PD Information Specialist.