

The Language of Parkinson's: Common Terms to Use with Your Doctor

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In December 2018, the U.S. Food and Drug Administration approved Inbrija (inhaled levodopa) for “off” time in Parkinson’s. Inbrija is designed to be used as needed for “off” time, in addition to one’s daily medication regimen. The Michael J. Fox Foundation supported early clinical trials of the treatment, and it is the first Parkinson’s therapy directly funded by the Foundation to come to market.

As more treatments for Parkinson’s disease (PD) become available for doctors to prescribe to their patients, it is important to review what “off” time really means, and how PD is discussed in research and care. For greater confidence in talking with your doctor and managing your symptoms, familiarize yourself with commonly used terms.



“Off” time: periods when Parkinson’s symptoms, movement or non-movement (such as anxiety, fatigue or mental foginess), re-emerge. “Off” time may occur:

- + in the morning, upon waking up and before the first dose of medication;
- + between medication doses, before the next scheduled dose (“wearing off”); and/or
- + suddenly and out of the blue.

Everyone who experiences “off” time has a different experience, such as:

- + significant stiffness and foot cramping in the morning;
- + a gradual return of tremor and anxiety 30 to 60 minutes before the next levodopa dose; and/or
- + unpredictable episodes in which they can barely move.

“On” time: periods when Parkinson’s symptoms are controlled. For example, after taking levodopa, tremor goes away or is barely noticeable.

Dyskinesia: uncontrolled, involuntary movement, which is often a writhing or other irregular movement in the limbs, torso or head. Dyskinesia is a potential complication of long-term levodopa use in people who have had Parkinson’s for many years. When it does occur, dyskinesia most often happens during “on” time. For example, after taking levodopa, stiffness and slowness may decrease but mild swaying of the head and chest (dyskinesia) may start.

Dystonia: an often-painful muscle contraction that pulls a body part into abnormal position. In Parkinson’s, dystonia can cause a foot to turn in or toes to curl under. Dystonia typically occurs in the morning or during other “off” time.

It can be hard to classify your symptoms or differentiate between tremor and dyskinesia, for example. It also can be tough to figure out if you’re experiencing “off” time and when. Videotaping your symptoms to review with your doctor and keeping a log of when you take medications and what symptoms you notice may be helpful.

For blogs and videos on the latest in Parkinson’s research and care, visit michaeljfox.org/ask-the-md.

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