

Survey Assessment: Impact of OFF Time on People With Parkinson's Disease and Their Care Partners



Parkinson's disease (PD) is the **second most common neurodegenerative disorder in the U.S.**, affecting nearly **1 million Americans each year** with an estimated **50,000 people newly diagnosed** with this disorder **annually**.¹

There is no cure for PD, and management of the disease largely consists of treatments such as carbidopa/levodopa that attempt to control motor symptoms, but as the disease progresses, the effects of these treatments begin to wear off more quickly.^{2,3}



ON TIME

Periods when the medication is working and motor symptoms are controlled



OFF TIME

When PD medication "wears off" and motor symptoms (e.g., tremors or stiffness) and/or non-motor symptoms (e.g., fatigue or pain) may return

The **Parkinson & Movement Disorder Alliance (PMD Alliance)** and **Neurocrine Biosciences** conducted a survey to uncover the awareness among people with PD and their care partners regarding the occurrence and impact of OFF time and available adjunctive treatments to address its symptoms.⁴

- Conducted by Ipsos* from **May 5–June 10, 2022**
- **240 adults age 18+** from continental U.S., Alaska, and Hawaii interviewed online in English
- **113 people with PD** who received a diagnosis of PD from a physician
- **127 care partners** of people with PD

** Ipsos, one of the largest market research and polling companies globally.*

People with PD and Care Partners Should Discuss OFF Time Symptoms with a Healthcare Provider

Despite a majority of these people with PD and care partners being significantly impacted by OFF time, there is a general acceptance that the emergence of OFF time is part of the disease, and they may not be aware of the availability and use of adjunctive treatment options for use to address return of PD symptoms.



86% of people with PD taking the survey experience OFF time daily, and a majority report it has a significant impact on activities



The findings suggest that despite experiencing OFF time symptoms, many people with PD may not understand and/or be aware that there are adjunctive therapies that can be used to address OFF time throughout the course of the disease and are thus settling for suboptimal treatment plans.



An opportunity exists for people with PD and their care partners to increase discussions with their healthcare providers about OFF time and stay informed about their treatment options upon return of motor symptoms.

While three in four people with PD (**78%**) report that their current treatment plan is effective at limiting their motor symptoms, a majority (**56%**) also say that they don't think their symptoms can improve beyond their current state.

N=113 patients with Parkinson's Disease



Misconceptions About Adjunctive Therapy⁴

Among people with PD and their care partners, there is a lack of knowledge and awareness regarding the availability, use, and benefits and risks of adjunctive treatment that can be used to address OFF time.

People with PD and their care partners should increase discussions with their healthcare providers about OFF time and stay informed about the potential benefits and risks of use of adjunctive treatment.

Nearly all of these people with PD said they are willing to explore new treatment options (96%) and would ask their doctor about adjunctive therapies (94%)

- However, nearly three-fourths (72%) mistakenly believe that adding adjunctive therapy means their PD is progressing
- While an increasing frequency of OFF time indicates disease progression, there is a misconception that adjunctive therapy is only used to address OFF time once the disease has progressed

N=113 patients with Parkinson's Disease

References:

1. Parkinson's.org. About Parkinson's disease factsheet. Accessed July 2022. <https://www.parkinson.org/sites/default/files/PD%20Fact%20Sheet.pdf>.
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4. PMD Alliance/Neurocrine survey conducted by Ipsos; May 5–June 10, 2022.