

Wake-Up Call: New Patient Survey Reveals Parkinson's Significantly Disrupts Sleep

Today, the PD Avengers, a Global Alliance to End Parkinson's Disease, released groundbreaking data from their SLEEP Survey.

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[/EINPresswire.com/](https://EINPresswire.com/) -- [PD Avengers SLEEP Survey](#) uncovers key areas for improving care for those living with Parkinson's and their caregivers

Today, PD Avengers, a Global Alliance to End Parkinson's Disease, released groundbreaking data from their Global "Surveying Late Evening Effects of Parkinson's" (SLEEP) Survey. The

survey, conducted from March 15th to May 15th, 2024, in collaboration with AbbVie, sheds light on the significant impact of nighttime symptoms on people with Parkinson's (PWP) and their caregivers. Responses from over 1,248 PWP and 286 caregivers across 27 countries, revealed the following key findings:

“

Our commitment to ending Parkinson's disease must be unwavering and all-encompassing, embracing every hour of the day and night.”

Larry Gifford, PD Avengers

night.

Common Symptoms: The five most common reported symptoms during sleep were: frequent awakenings (53%), insomnia (50%), bradykinesia (41%), rigidity (38%), and nocturia (38%).



Difficulty with Movement: 65% of PWP's reported difficulty turning over in bed at night and this increased to 84% for those who identified as having advanced PD.

Gender Differences: Men reported higher instances of nocturia (43%), drooling (30%), and REM Sleep Behavior Disorder (28%), while women were more affected by insomnia (55%), joint stiffness (27%), and excessive sweating (28%).
Healthcare Practitioners Engagement:

Discussions on Sleep with Healthcare Providers: Nearly 30% PWP's reported their HCP did not engage in discussions about sleep and only 20% have received a diagnosis for a sleep disorder.



Insomnia, restless legs syndrome, and REM sleep behavior disorder are just a few issues people living with Parkinson's contend with each night.

Regional Differences: North American respondents are more likely to receive a sleep disorder diagnosis (24%) compared to their European counterparts (13%).

Impact on Caregivers: Daily Functioning: A significant majority, 88%, of caregivers experience some level of sleep disruption due to their partner's Parkinson's disease, ranging from moderate to severe impacts.

Emotional and Physical Strain for the PWP and Care Partner Relationship: 44% of PWP's report that nighttime symptoms significantly impact their care partner emotionally, while 36% of PWP report that their symptoms disrupt their care partners sleep and physical well being

40% of caregivers experience significant emotional burden, and 34% report significant sleep disruptions to assist with movement or medication.

Additionally, 32% feel constant concern for their care recipient's well-being, leading to heightened vigilance and difficulty relaxing.

"The nighttime struggles of PWP's and their caregivers are a silent crisis that demands attention. It's not just about acknowledging these challenges but taking actionable steps to address them. Our commitment to ending Parkinson's disease must be unwavering and all-encompassing,

embracing every hour of the day and night." – Larry Gifford, President and Cofounder, PD Avengers.

Parkinson's disease (PD) is the fastest growing brain disorder in the world and impacts 11.8 million people³. While PD is often characterized by motor symptoms such as tremor, muscle rigidity, and difficulty with movement, it also presents over 40 potential symptoms⁴ with sleep, pain, gut health, and constipation. Many of these symptoms are hidden from others including anxiety, depression and apathy.

To address these issues, the PD Avengers recommends the following actions:

1. Improve Communication Between PWP's and HCP's: Encourage more proactive discussions about sleep issues to ensure that PWP's receive comprehensive care.
2. Support Caregivers: Establish respite care, support groups, and counseling services immediately to alleviate the immense emotional and physical strain on caregivers. They need relief and support, not just acknowledgment.
3. Deploy Assistive Technologies: Promote the rapid adoption of assistive devices that enable PWP's to manage nighttime symptoms independently, reducing caregiver intervention and improving sleep quality.
4. Drive Education and Awareness: Increase education efforts among healthcare providers about the critical importance of diagnosing and managing sleep disorders in Parkinson's. Equip PWP's and caregivers with the knowledge to advocate for proper care.
5. Advocate for Policy Change: Push for flexible work arrangements and financial assistance programs for caregivers who are financially strained due to their responsibilities. Policy change must support the well-being of both PWP's and their caregivers.

Find more data and results on the 2024 SLEEP Survey at <http://www.pdavengers.com/sleepsurvey>. This is the first of our monthly releases on SLEEP data.

OPEN SOURCE SURVEY RESULTS

ENGLISH https://www.surveymonkey.com/stories/SM-qy72_2FiQgrUjK0ej2EIE38g_3D_3D/

FRENCH https://www.surveymonkey.com/results/SM-6vWl8LjkwO8SUjDBKV4gQg_3D_3D/

SPANISH https://www.surveymonkey.com/stories/SM-er5ipO1Z8phPPs_2B6C0f_2F0A_3D_3D/

ITALIAN https://www.surveymonkey.com/results/SM-ii3v_2FIMw6QQyGWMuFV1HvQ_3D_3D/

PORTUGAL https://www.surveymonkey.com/stories/SM-ahqMBC_2F9wBq_2BYZVdfUjB4g_3D_3D/

GERMAN https://www.surveymonkey.com/stories/SM-rYqcThhE5NNFUhe0VbEtTQ_3D_3D/

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www.pdavengers.com/sleepsurvey

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PD Avengers

The PD Avengers is a global alliance of more than 8,300 people and 150 partner organizations in 103 countries affected by Parkinson's Disease (PD), including patients, caregivers, researchers, advocates, and healthcare professionals, who are united in their mission to end Parkinson's. Through three pillars of wellness, advocacy and research, PD Avengers is adding urgency to the cause with an aim to raise awareness, drive research, and advocate for better treatments and care. It uses various initiatives, campaigns and events to amplify the voices of those impacted by Parkinson's and advocate for positive change in policies and practices related to PD.

AbbVie in Neuroscience

At AbbVie, our commitment to preserving personhood of people around the world living with neurological and psychiatric disorders is unwavering. With more than three decades of experience in neuroscience, we are providing meaningful treatment options today and advancing innovation for the future. AbbVie's Neuroscience portfolio consists of approved treatments in neurological conditions, including migraine, movement disorders, Parkinson's disease, and psychiatric disorders, along with a robust pipeline of transformative therapies. We have made a strong investment in research and are committed to building a deeper understanding of neurological and psychiatric disorders. Every challenge makes us more determined and drives us to discover and deliver advancements for those impacted by these conditions, their care partners, and clinicians. For more information, visit www.abbvie.com.

¹ SLEEP Survey www.pdavengers.com/sleepsurvey

² PD Avengers www.pdavengers.com

³ [https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(24\)00038-3/fulltext](https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(24)00038-3/fulltext)

⁴ Parkinson's disease - Symptoms and causes - Mayo Clinic

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