Parkinson's Disease in the LGBTQ+ Community: Three Things to Know



Parkinson's is a brain disease that impacts each person differently.

Parkinson's disease (PD) occurs when brain cells that make dopamine, a chemical that coordinates movement, stop working or die. Because PD can cause tremor, slowness, and walking and balance problems, it is called a "movement disorder." But constipation, smell loss, depression, memory problems and other non-movement symptoms also can be part of Parkinson's.

+ More than six million people worldwide live with PD.

There is no single known cause for PD, but some factors may put certain people at a higher risk for developing the disease. Risk factors include ongoing smell loss, REM sleep behavior disorder (acting out dreams while asleep), having a first-degree family member with Parkinson's, being exposed to environmental toxins, serving in the military and aging. However, having a risk factor does not guarantee disease.

More research is needed to better understand how Parkinson's affects the LGBTQ+ community.

Research shows that the LGBTQ+ community experiences higher rates of depression, anxiety, isolation and body image issues. It can be particularly difficult for members of this community to receive a PD diagnosis without the proper resources.

+ There is still much to be learned about how LGBTQ+ people experience PD.

Due to fear of discrimination, LGBTQ+ patients often avoid the appropriate care, leading to delayed diagnosis. This is important because early and frequent medical care for people with PD can have significant health benefits. LGBTQ+ people may experience stigma and feel additional pressure to disclose their gender identity or transition status at medical appointments.

Transgender people are often the most overlooked by medical professionals out of the LGBTQ+ community as a whole, with 50 percent reporting prior mistreatment when receiving medical care. Because of PD symptoms such as soft voice and stooped posture, transgender individuals may be at risk for increased gender dysphoria.¹ Additionally, some doctors may not be well versed in gender-affirming care. They may be unable to provide the multidisciplinary resources that transgender people with PD need. The role of hormones in PD is also unclear. Testosterone has not been found to affect symptoms while in a few studies, estrogen therapy has shown protective benefits.²

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Movement disorders is one of the least researched areas in LGBTQ+ neuroscience. Most research in the community focuses on movement disorder symptoms associated with HIV/AIDS.³

Some barriers to LGBTQ+ research participation include mistrust stemming from a history of judgment and discrimination and fears of being outed, logistical barriers such as transportation⁴ and researchers' lack of cultural competence.⁵

Despite these challenges, research participation could not be more important going forward. Parkinson's can impact anyone, regardless of identity.

+ By participating in research, you play a role in better brain health for all.

The Michael J. Fox Foundation for Parkinson's Research (MJFF) is committed to inclusive research and advancing cures for all, including communities who have been historically underrepresented in Parkinson's research.



The Parkinson's Progression Markers
Initiative (PPMI) is MJFF's landmark
study on a mission to better treat
and prevent disease. PPMI is enrolling
people with and without PD.

Learn more and join the study that's changing everything at michaeljfox.org/ppmi-community.

MJFF is also funding a study at the University of Nevada.

The study is interviewing members of the LGBTQ+ community to help improve the health and care of people with PD. Surveys and interviews can be done by phone at **1-888-709-7689** or by emailing Jason Flatt, PhD, MPH at **Jason.flatt@unlv.edu**.

References

- 1. LGBTQ+ & Parkinson's. Link to source.
- 2. The effect of estrogen in a man with Parkinson's disease and a review of its therapeutic potential. Link to source.
- 3. Expanding sexual and gender minority research in movement disorders: More than awareness and acceptance. Link to source.
- 4. Perceptions of Barriers to and Facilitators of Participation in Health Research Among Transgender People. Link to source.
- 5. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. Link to source.

