

# For People Living with HIV, Self-Advocacy Can Make All the Difference



Guy ANTHONY



Octavia LEWIS

In the U.S., there are approximately 1.2 million people living with HIV (PLWHIV),<sup>1</sup> many of whom have experienced stigma and discrimination when accessing care. In the LGBTQ+ community, 15% of people report postponing or avoiding medical care or treatment due to discrimination, an indication of what is referred to as “medical mistrust.”

Medical mistrust, or a lack of trust or comfort with the healthcare system, medical practitioners or medicine, has been a pervasive issue in the LGBTQ+ and historically underrepresented communities, and can be a significant obstacle to getting care.

HIV stigma can negatively affect the health and well-being of PLWHIV, resulting in depression, isolation, and discouragement from seeking care or staying on HIV medication.<sup>2</sup> Similarly, HIV discrimination can inhibit a positive interaction with healthcare providers and limit the effectiveness of HIV care.

Octavia Lewis, a transgender woman of color living with HIV, reflects on her experience feeling medical mistrust. “I was in a situation where I felt my healthcare provider was not interested in what I was experiencing or my needs, which was discouraging,” she explained. “I did not feel seen, heard, or validated.”

This is exactly the type of scenario where a patient may disengage from care. In Octavia’s case she switched physicians; however, not everyone may be motivated to do so.

With the right healthcare provider, patients come to feel treated with dignity, trusting enough to talk about their barriers and supported in their ability to manage their health.

For example, in another scenario, Octavia praised a physician for showing a human side and working collaboratively to find the best healthcare solutions. “[My physician] didn’t know how to provide hormonal care to trans patients. She was very transparent about it, and I loved that about her,” Octavia said. “She did her homework, she was diligent, and it was a journey we went on together.” As there is no precedence for transgender or gender affirming care, this honesty and willingness to learn supported a productive partnership.

The Center for Disease Control National HIV Behavioral Surveillance survey among 1,608 transgender women showed that comfort with a provider can help alleviate the stigma and discrimination that often deter transgender persons from seeking care.<sup>3</sup>

In addition to being transgender, medical mistrust for PLWHIV becomes more compounded for people of color, including Black and Latinx individuals who are disproportionately impacted by HIV, accounting for approximately 70% of new HIV infections.<sup>4</sup>

A history of discrimination in the Black and Latinx communities prevent many from seeking healthcare at all. Culture, societal norms, and religion may also be a barrier to proper testing, prevention, and treatment of HIV. Without a full picture of the risks and benefits of HIV medications, medical mistrust may be further exacerbated.

As an example, Black and Latinx PLWHIV are at the highest risk for anti-retroviral (ARV) treatment-related weight gain. And yet, research shows that while 85% of Black and Latinx PLWHIV want to discuss treatment-related weight gain with their physicians, only 38% can recall having this discussion.<sup>4</sup>

Guy Anthony, author of *Positively Beautiful*, and a Black queer man living with HIV, says his experience with medical mistrust is what drove him to become an advocate for himself and others. “Historically, my community never really had access to comprehensive healthcare, and in addition, many of us are religious and there is still a stigma attached to talking about sexual health,” he said.

Diagnosed with HIV at 19, Guy recalls hosting a dinner party for friends when he realized that many of the guests were living with HIV, but no one was talking about it. This was one of the experiences that led him to change his career focus and become an advocate. “I felt Black PLWHIV needed someone who understood their journey living with HIV,” he said. “I’m of a different generation. I fight for myself. I interview doctors as I interview for a job, understanding they are also working for me.”

## An Opportunity for Conversation

Octavia and Guy recognize that over time, walls have been built that aren’t always easy to take down. The fact is, PLWHIV face real challenges in having direct conversations about their health with family, friends, and healthcare providers.

“Medical mistrust is an opportunity to stop and have conversations,” Octavia said. “We need to be self-advocates, we need to have awareness of our surroundings, of our discomfort, and take our power back.”

“People can be more afraid of the stigma than the actual disease,” Guy adds. As advocates and ambassadors for *Positively Fearless*, a program that supports the HIV community with resources and empowerment, Octavia and Guy encourage others to self-advocate and aim for the best possible health outcomes. They believe that with strength and determination, “brave talks” are in reach for anyone.

## Tips to Self-Advocate

It takes courage to overcome barriers associated with having an open conversation. Here are some tips from the *Positively Fearless* ambassadors for being a strong self-advocate and prioritizing your health:

- Lean into what is uncomfortable – you will be surprised at how far that takes you.
- Before meeting with your healthcare provider, think through questions and prepare to approach conversations with honesty and vulnerability.
- View disappointments, criticism, and doubts as par for the course – they are all just part of the path to healing and success.
- Educate yourself on the policies surrounding HIV care, which can vary state by state and impact your care.
- Above all, know you have a basic human right to healthcare that meets your needs.

## A Guide to Having Brave Talks

Self-care looks different for everyone, which is why having open conversations is critical. Being transparent about your health can help a healthcare provider recommend the right treatment path and support your complete care, including physical, social and mental health.

Access and download a free discussion guide on [\*Having Fearless Conversations With Your Healthcare Provider\*](#) from **PositivelyFearless.com**.

This article is sponsored by Janssen Pharmaceuticals, Inc.

<sup>1</sup> U.S. Statistics Fast Facts. HIV.gov. <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>. Published June 30, 2020. Accessed July 5, 2022.

<sup>2</sup> HIV Stigma and Discrimination. Centers for Disease Control and Prevention. <https://www.cdc.gov/hiv/basics/hiv-stigma/index.html>. Published June 1, 2021. Accessed July 5, 2022

<sup>3</sup> Lee K, Trujillo L, Olansky E, et al. Factors Associated with Use of HIV Prevention and Health Care Among Transgender Women – Seven Urban Areas, 2019–2020. *MMWR Morb Mortal Wkly Rep* 2022;71:673–679. DOI: <http://dx.doi.org/10.15585/mmwr.mm7120a1>

<sup>4</sup> Data on file. Janssen Pharmaceuticals, Inc.