The Freedom to Be

Switching HIV regimens from a daily oral pill to a monthly injectable has given Alex Vance more headspace.

May 17, 2021 By Tim Murphy

Alex Vance is not your ordinary person living with HIV. The 32-year-old advocate also deals with the virus daily in their work as an independent HIV and LGBTQ health and policy consultant. Before that, at the national organization AIDS United, they helped create a 134-page document titled "Ending the Epidemic in the United States: A Roadmap for Federal Action." And before that, they headed advocacy and policy for the group AIDS Alabama.

"I'm really interested in finding what people's barriers are to getting and staying on HIV medications," Vance says, "because once people have well-controlled HIV, they live a normal life, and we also reduce community viral load, which reduces HIV incidence." As part of their work, Vance reads countless formularies (lists of covered drugs) in state health plans, which include Medicare, Medicaid, the AIDS Drug Assistance Program (ADAP) and private insurance.

In other words, Vance is a big HIV policy geek. But HIV is also personal for them. Their HIV positive diagnosis in 2009 prompted them to leave a customer service job and plunge into HIV activism. That step was foreshadowed by their mom, who volunteered in the field decades ago. "I watched her cry when her friends died when I was a kid," Vance says, "so there were always these touches of HIV in my life before it personally affected me."

Vance went on meds a year after their diagnosis and has used only one-pill-daily regimens, all per the recommendation of their health care provider. Although side effects have been limited to "terrible technicolor dreams" while on one of those regimens, they still struggled intermittently with adherence.

"There have been a handful of times I've missed a day or two over the past years, which fed my already existent anxiety," Vance says. So when they learned in early 2021 that the Food and Drug Administration had approved Cabenuva—the first long-acting injectable treatment, which requires a monthly doctor's visit—Vance was interested.

Vance and their provider completed the enrollment form from ViiV Healthcare, the drug's maker. Currently, most health plans, both public and private, are not yet covering Cabenuva, so Viiv is providing it for free—including the mandatory first month's worth in daily oral form—to folks without coverage. That way, in the event of bad side effects, the drug will "wash out" of one's

system faster than if it were initially given via injection.

Vance had no issues with the first month's oral form, so in late April, they had their first injections—one shot each of the two drugs that make up Cabenuva, both in the same buttock. Moderate soreness ensued for the next day and a half, Vance says, "but that doesn't deter my feelings at all—next time, I'll get one shot in each butt cheek."

A few days later, Vance looked at the pill sorter in their bathroom. "I thought, There's one less pill in there for me to worry about. Now I feel like HIV is even less a part of my life." What's more, they are optimistic about data suggesting every-other-month injections are equally effective—not to mention other injectable options further down the line that may be even less frequent or self-administered at home.

Vance is aware of their privilege. "We're part of a lucky generation treatment-wise. My mother still talks about the people she lost." Vance hopes that injectables like Cabenuva soon become available in poorer countries, where many people, because of cultural stigma, fear that others may discover their HIV pills. "I'd like to see how injectables could be used to curb the epidemic in the Global South," Vance says, referring to countries in Latin America, Africa and Asia.

Meanwhile, Cabenuva has allowed Vance to spend less time thinking about their own HIV and more time thinking about HIV in the macro sense, for work. Being on injectables has also allowed Vance to simply enjoy life in Washington, DC, which they share with two boyfriends and their dog, Cotton, a 2-year-old deaf pit bull. "If we're not napping on the couch together, we're walking around Capitol Hill."

Vance loves their new freedom. "HIV has been part of my daily life for a long time, but now I can give my full self to everything else—work, play or anything."

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