I Stopped Taking My HIV Pills

Long-acting injectables made Josh Kruger rethink HIV treatment, activism and the size of his butt.

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“My only concern,” my doctor said to me with a tremendously heavy pause, “is that you’re working with a lot back there.” This was the politest way I’ve ever heard someone say I have a fat ass.

I could see why he approached the topic so deliberately. One of the best HIV doctors in Philadelphia, he was part of the Cabenuva approval study here and is now also an expert at dealing with my mercurial personality and occasional, sometimes warranted and sometimes not, outbursts.

I had been excited about the prospect of the new injectable HIV medication Cabenuva, so any concern—let alone this concern—was a touchy subject. Besides, my mom used to buy me jeans from the husky section at JCPenney’s. And while my doctor’s observation is today truly a compliment based upon feedback from men I date, it’s still a subject fraught with anxiety and insecurity.

It’s sort of like my relationship with HIV. It’s not that I ever wanted to be HIV positive. But it’s so a part of who I am now that, well, it’s complicated.

For about a decade, I’ve been taking one pill, once per day every day. I’ve never noticed any side effects, though one could argue some weight gain might’ve been attributed to them.

Basically, adherence has been part of my life. Getting access to my meds when I was unemployed, uninsured, even homeless at one point, wasn’t just a key priority. It was the priority.

As a result, I’ve experienced few if any HIV-related complications. And while there’s still so much work to do—just over half (55%) of HIV-positive people in Philadelphia, where I live, are on treatment and virally suppressed—there are plenty of cases where things are going as planned. Nationwide, the figures are only slightly better, at 64%.

Even so, the idea of tossing the pills entirely for a visit to the doctor once every two months was going to take some getting used to, albeit now jeopardized by a flesh-and-blood peach emoji.

“My ass is so fat you’re concerned I can’t take the injection?” I asked, bemused. I gained weight

during the quarantine, but was it really that much?

“No, no, we can do this,” he assured me. “We just have to make sure. We might need a bigger needle.”

“I say that to dates all the time,” I quipped. Balance the tragedy and trauma with a cheap laugh, I say.

All bad jokes aside, the new rhythm of treatment would take some getting used to.

First, we have to make sure I’m still undetectable, as I’ve been for almost a decade. Then, we schedule the day for the first treatment—two injections, one into the muscle on the upper part of each cheek. I should continue to take my pills about four days after the first treatment before stopping entirely. Thirty days later, I get another two injections as part of my starter dose. After that, I go every two months for the same treatment, all the while getting my blood drawn to make sure everything is going as planned.

Simple. Kind of?

Having repeated the “one pill once per day” mantra for nearly a decade, my first impulse was to embrace the supposed freedom of no pills at all. Pill-based treatment seems simple, but those viral suppression figures tell a different story. Plainly, if it’s so simple, why are so few people undetectable?

Hinging lifesaving care on one’s ability to maintain access to medication and take that medication, no matter what, every single day is great until you can’t do that anymore. More to the point, you can’t take your meds if you don’t have a place to store them. It’s hard to get something refilled if you’re too depressed to do the things necessary to stay connected to care.

In one study published in February 2022’s BMC Infectious Diseases, researchers found that “homeless patients were half as likely to achieve viral suppression as compared to those who had a permanent or stable home.” Researchers, including Vladimir Berthaud, MD, MPH; Livette Johnson, MD; and Ronda Jennings, reported that study participants who were undetectable, with a viral load of less than 20 copies of HIV per milliliter of blood, were overwhelmingly stably housed.

“While 74% of permanently housed patients reached viral suppression,” they wrote, “a much smaller proportion of the homeless patients (54.7%) remained virally suppressed.” Having been homeless myself, I know too well the difficulty posed by maintaining HIV treatment while trying to fix everything else.

So it makes sense to circumvent the process entirely with the injections. Yet even in studies where the injections are given high marks by consumers, their efficacy is more or less the same as the pills in terms of HIV treatment. Conversely, emerging studies of injectable medications used as pre-exposure prophylaxis (PrEP), where HIV-negative people take medication to prevent HIV, show that injections are even more effective than their pill counterparts.

The record, then, puts injectables in an equal or superior place than traditional treatments. This makes it a particularly effective tool in the "HIV treatment and prevention toolbox" that advocates and providers so often talk about. Of course, injectables won't end the epidemic. No single treatment will. But they seem to offer an alternative intervention that HIV-positive consumers prefer—in one study, 98% of people preferred Cabenuva over their previous pill regimen—that's also even more effective at preventing HIV among HIV-negative people.

Still, the idea that people will be able to more readily schedule appointments months in advance and follow through is not exactly an established fact. It's possible that the people most likely to benefit from and need bimonthly injectable HIV medication—those with intermittent connections to care or unstable housing or who are members of traditionally underserved communities—are going to be the least likely to adopt Cabenuva as a treatment.

Whether we've learned anything from PrEP access and can apply that to Cabenuva isn't yet clear. But we're missing an opportunity if we don't. "Black people in the U.S. represent less than 10% of PrEP prescriptions, but we represent 40% of new HIV cases," national HIV consultant Leisha McKinley-Beach explained to WordInBlack.com writer Alexa Spencer. "You know, something is wrong with that picture."

Unless America finally gets serious about its equity efforts, the same structural barriers and problems we find in treatment or PrEP access overall will likely plague injectables, regardless of how much people on injectables say they prefer them.

This doesn't mean they're something to dismiss as irrelevant to all but the most privileged, though. In my case, while I am a cisgender white guy, I'm also currently accessing the treatment via Medicaid while living in America's poorest big city.

For me, around the 29th of every month is treatment day. I can't go more than a week before or after that date. So I check to see if treatment is that month or if it's one of my "byes," as the NFL calls its off weeks. I break it down this way so I can remember and explain it to people.

Part of me doesn't trust it. What if my ass really is too fat? No pills? No "proof" I'm being treated and not just saying I'm undetectable as some people worry about? Being under 40 with a grandma-style pill organizer is something I won't miss, but it's been part of my life all this time. When the pills go, does part of who I am go with them?

These questions are trivial, though, when you zoom out to the entire HIV-positive population.

If those figures for viral suppression are what they are now, will they improve as more people switch to Cabenuva or similar treatments with such a relatively complex process to start? And if someone has trouble with adherence to something as simple as one pill once per day, what are the chances they'll remember "two injections done twice separated by 30 days and then one two-injection round every 60 days thereafter?"

And have we started learning anything about equity and treatment access, or are we just churning out reports with recommendations to meet diversity and inclusion requirements that come with federal grants—and then leaving those reports in drawers or on rarely visited PDF download pages hosted by state and local public health agencies?

At the end of the day, these heady concerns weren't strong enough to overcome the clear scientific evidence showing that Cabenuva is, arguably, superior to pill regimens. I was sure I'd regret not at least trying it.

"So are we doing this?" my doctor asked me.

We worked out a day for me to come back. I had to get my levels checked again. Once that came back fine, the order would be put through the pharmacy, though the treatment is done in the office. Suddenly, I got nervous again. It was more of an excited nervous, to be sure.

The data were just too convincing, so I ignored the jitters and prepared to never again have to say, "I take one pill once per day" in reference to my HIV treatment.

Now, it would be, "I get two shots once every other month."

Maybe it's not a slicker slogan. But, based upon the research, I'll have a near 100% chance of preferring it.
