My Journey to Treating HIV Without Pills

Learning about long-acting injectables is Jay Lassiter's New Year's resolution.

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I've been HIV positive for over 30 years and started taking HIV medication in 1997. The memories of that day, and of the first fistful of pills, are quite vivid all these years later. There was immense relief and gratitude that I might not die of AIDS. I recall the apprehension about the side effects I'd heard about. But mostly, I was dumbstruck noticing how enormous those pill bottles were, three of them, each the size of a quart of milk.

And the pills inside, those were awfully big too.

Since my initial antiretroviral therapy (ART) cocktail included 20 pills a day, those bottles contained 600 pills, a monthly regimen that added up to 7,300 pills per year, just to treat HIV.

Like most HIV long haulers, my journey includes multiple iterations of ART.

The circa 2004 transition from 20 pills a day down to 12 felt truly revolutionary. Since then, my daily dose has winnowed from 12 huge pills to six and then to just two tablets, each smaller than a Tic Tac.

Today, one tiny pill keeps my HIV in check and my immune system humming with no side effects. Speaking of which, despite their lifesaving properties, those early treatments had their downside.

My first cocktail of HIV meds landed me in the ER with anemia.

With my second cocktail, the side effects often felt like a nasty hangover: nausea, vomiting, headache, dizziness. There were sudden hot flashes and night sweats that turned into chills that left me convulsing with shivers.

And diarrhea: profoundly humbling and unpredictable and frequently in charge of my life at that point.

Waking up soiled, panicked and dehydrated was humiliating. And in my case, a predictable thrice-a-week reminder that I was wasting away to skin and bone. I'm still haunted by the memory of my

emaciated reflection staring back at me in the mirror, a gaunt-looking witness to my own toilet-bound disintegration.

To add insult to injury, there was a dirty bed linen situation to manage before going back to bed. It's traumatic to reflect on, but at the time, I earnestly did my best to just manage and get on with it. We were the lucky ones, and all those nasty side effects were the price we paid not to die of AIDS.

But that was then. And blessedly, HIV management has come light years since then.

In January 2021, the Food and Drug Administration approved the first complete long-acting injectable treatment for HIV-positive adults and adolescents with an undetectable viral load who wish to change their regimen.

Initially intended as a once-a-month injection, subsequent clinical trials extended that window from 30 to 60 days. Studies have shown that the two-drug regimen is also effective for people starting treatment for the first time. Those Phase III clinical trials dramatically expanded the pool of people who might benefit from injectable ART. Additional long-acting injectables are currently in clinical trials, and one is currently approved for heavily treatment experienced people with drug-resistant HIV.

Michael Zito-Govert, DNP, is an HIV-positive nurse practitioner. He's also a clinical manager for the Ryan White HIV/AIDS Program at the Visiting Nurse Association of Central Jersey in Asbury Park and Freehold. His caseload of over 200 patients includes 17 individuals on long-acting injectables. Another patient is transitioning to the regimen.

Zito-Govert notes that his patients often fall into one of two camps: those eager to embrace novel meds right away and those waiting for the 60-day efficacy window to expand to 90 or even 180 days, something Zito-Govert predicts is likely on the horizon.

"Some folks want to jump right in, and others wait until it's fine-tuned a bit more," Zito-Govert says. "For many, the option of not taking a daily dose is appealing—to not have a daily reminder of being HIV positive. Some folks don't want others to know they're taking pills—those who live with family members or roommates who don't need to know. Some folks have housing insecurity or mental health barriers. And carrying around a bottle of pills when you're living out of a bag is sometimes just not possible."

In addition to the unhoused population, Zito-Govert cites those with unpredictable schedules—for example, pilots and flight attendants and shift workers—as populations for whom injectables might be especially well-suited.

Zito-Govert notes that injectables may be especially appealing to people not taking other meds who therefore could avoid visits to the pharmacy altogether. Someone like me.

I just started a 90-day refill of my current one-pill regimen. So as someone interested in switching

to long-acting injectables, I have a few months to figure it out.

As it turns out, having a month or two to figure it out is probably a good thing.

“Approval is a bit of a process,” Zito-Govert adds. “That window gives us time to know if this treatment is ideal for the patient.”

Currently, the regimen requires visiting the clinic every two months for injections. That could be a barrier for some patients, but Zito-Govert sees it as an opportunity.

“The added benefit to having them in every two months is an opportunity to catch and treat them and connect them with someone like a case manager,” Zito-Govert says. “One of the great things about being able to get them in is to get them connected to any level of care they need, including mental health, addiction, harm reduction, when they’re at the clinic. Because it requires more frequent visits, assessing the patient’s access and ability to commit to coming in and getting the injections is paramount. We need to make sure there are no barriers to transport and timing.”

Patients might also need time for an oral lead-in, which, for Zito-Govert’s patients, usually lasts about three to four weeks.

“Injectables are a long-acting medicine,” Zito-Govert explains. “Oral lead-in is when patients take oral tablets for the same medications [they’ll be injecting]. So you’ll take two pills a day for two to three weeks to ensure there’s no sensitivity. If there’s a sensitivity, those few weeks on shorter-acting oral tabs are the best time to sort that out.”

According to Zito-Govert, an “oral lead-in” is not required for this injectable regimen, but many clinicians prefer to do it as part of the transition to injectables anyway.

Zito-Govert also points out that each visit includes two shots: “One in each [butt] cheek,” he adds.

Having learned more about injectables, I’m inclined to transition to this injectable regimen and have gone so far as to email my doctor with preferences (e.g., the oral lead-in) for what I’d like the transition to look like.

At this point, it’s just a question of when.

“It’s not just about taking away the pills,” Zito-Govert concludes. “This treatment is about a commitment to a higher level of self-care.”
