



Saying Goodbye to Urgency

Switching to long-acting injectables to treat HIV could eliminate debilitating side effects.

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Jorge Chavez remembers being awakened many nights by a rumble in his stomach. Instead of sleeping peacefully, as he should have been, in his Minnesota home, he often had the urge to use the bathroom right away. It was a side effect of his HIV medication, one he'd faced almost every day during his years on the pill-a-day regimen: diarrhea.

Though he tried to keep it together, he was overcome with emotion when he had to take these late-night bathroom breaks. His bowel movements were so bad and the pain so great that he would end up sobbing over the toilet.

"I'm a very sensitive person," says Chavez, who is 43. "I'm a crybaby. I cry a lot." He adds, "I would say in my head, I know it's the pill. I know it's the pill."

Chavez had experienced side effects from his medication since taking his first HIV pill shortly after his diagnosis in 2010. At first, when he was taking three pills a day, he experienced constant insomnia, which often left him unable to concentrate during the day. As his regimens evolved so did the aftereffects of taking his medication daily, but eventually, that all changed when he switched to long-acting injectables.

Chavez, who was born in Acapulco, Mexico, moved to Minnesota 23 years ago. Prior to relocating there, he had been a medical school student. But when his family could no longer afford tuition, he quit his program and moved to the United States to work. Now, he's an onsite support and safety specialist at Minneapolis's Aliveness Project, an AIDS service organization where he has worked for four months.

Chavez was diagnosed shortly after moving in with a partner, whom he believes was not forthcoming about his HIV status. His diagnosis led to bouts of depression and excessive drinking. He feared how his friends and family might react to the news.

"I got really sad. I got upset. I got broken," he says. "In my head, I thought people were going to be pointing at me, like Oh, he has HIV!" Chavez adds. "Often in the Latino community, if you have HIV, you're [considered] a bad person."

Eventually, Chavez showed up to a doctor's appointment drunk and was charged with a DUI,

prompting him to turn everything around. At the time, he was undocumented, and his drinking was threatening his citizenship.

“The whole situation got really bad,” he says. After his attorney told him he needed to take better care of himself, he broke up with his boyfriend and started seeing a personal counselor to address his drinking. Chavez became a citizen in 2023.

While he had addressed so many of the other problems that had sprung up following his HIV diagnosis, the diarrhea persisted. “I was always getting in a bad mood, and I didn’t want to touch anybody,” he says. “I felt gross.”

Chavez altered his diet and gave up lactose to ameliorate the issue, but nothing worked. Still, Chavez remained on his one-pill-once-a-day regimen because he was no longer experiencing insomnia or fatigue and was full of energy.

When he finally broached the topic of his side effects with his doctor, a series of tests followed. He had to describe his bowel movements to help his physician eliminate other possible causes, such as bacteria or diet. He was honest with him about just how much the side effects interfered with his everyday life. His doctor was hesitant to switch and had Chavez undergo months of testing. Eventually, Chavez saw an ad for a long-acting injectable on Facebook.

“I was really excited,” Chavez says “I was like, This is going to fix all my poop problems.” He spoke to his doctor about switching and he eventually agreed.

Chavez was most excited to no longer have an adverse relationship with his medication. He would sometimes go off his medication while traveling, especially while visiting his family in Mexico. He didn’t want his trips home to be disrupted by diarrhea.

Prior to receiving his first injection, he, as everyone must, took the pill version of the medication as a lead-in to taking the drug via injection. As soon as he switched to that drug, his diarrhea stopped.

At his first injection appointment, Chavez’s care team told him that the most common side effect was pain at the injection site. Chavez can remember feeling the medication entering his body through the needle. He didn’t experience any major discomfort at the time, but an hour later, he developed a fever and pain in his leg. It got to the point that Chavez wondered whether the needle had struck a nerve or a tendon.

“I wasn’t able to walk,” he says. “I wasn’t able to cross my legs. I was crying.”

Chavez went to urgent care on the third day after the injection and was prescribed a muscle relaxer. He later called his doctor, who recommended that he take ibuprofen. After five days, he woke up without pain. Despite the harsh side effect, he was determined to remain on the long-acting injectable treatment. But Chavez’s doctor considered the pain to be too much and put him back on his once-a-day pill.

Determined to get back on long-acting treatment, after two months and more diarrhea, Chavez called his doctor.

“I really want to try it again,” he says. “The first time was a lot of pain, but I feel like the second time is going to be less pain. And I really love having no side effects after.”

His doctor let him go back to the injections, and this time, rather than five days of pain, he experienced only three and the diarrhea ceased. By the third injection, the pain was milder and lasted less. Eventually, though he continued with his long-acting injectable, he switched care teams. His new team has slightly adjusted where he receives the injection, which has helped to almost eliminate the pain.

“One inch makes a lot of difference,” Chavez jokes.

Long-acting injectables, he says, have been a boon to his mental health as well. Not only has he stopped worrying about diarrhea, but he also doesn’t have to worry about the daily pill anymore. When he visits family, he no longer has to stop taking pills in order to manage his side effects.

“I don’t get sad,” Chavez says. “I don’t stress, and I don’t worry. Every single day with diarrhea, I was like, This is getting worse and worse.” He adds, “Right now, it feels like I don’t even have HIV.”