TuSalud

To Knock Down Health-System Hurdles Between You and HIV Prevention, Try These 6 Things

Most private insurance plans and Medicaid programs are required to cover PrEP and ancillary services like lab tests with no cost sharing.

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When Matthew Hurley was looking to take PrEP to prevent HIV, the doctor hadn't heard of the medicine, and when he finally did prescribe PrEP, the bills sent to Hurley were expensive … and wrong. "I decided to write in because the process was really super frustrating." At one point, Hurley asked, "Am I just going to stop this medication to stop having to deal with these coding issues and these scary bills?"

— Matthew Hurley, 30, from Berkeley, California

A couple of years ago, Matthew Hurley got the kind of text people fear.

It said: "When was the last time you were STD tested?"

Someone Hurley had recently had unprotected sex with had just tested positive for HIV.

Hurley went to a clinic and got tested. "Luckily, I had not caught HIV, but it was a wake-up call," they said.

That experience moved Hurley to seek out PrEP, shorthand for preexposure prophylaxis. The antiretroviral medication greatly reduces the chance of getting HIV, the virus that causes AIDS. The therapy is 99% effective at protecting people against sexual transmission when taken as prescribed.

Hurley started PrEP and all was well for the first nine months — until their health insurance changed and they started seeing a new doctor: "When I brought PrEP up to him, he said, 'What's that?' And I was like, oh boy."

Hurley, who is a librarian, went into teaching mode. They explained that the PrEP regimen they'd been on required daily pills and lab work every three months to look out for breakthrough

infections or other health issues.

Hurley was surprised they knew more about PrEP than the physician. The FDA approved the first drug, Truvada, back in 2012, and Hurley lives in the San Francisco Bay Area, a place with one of the highest concentrations of LGBTQ+ people in the nation and a deep history of HIV and health care activism. Hurley said older friends and acquaintances who survived the AIDS epidemic shared the horror of living through a time when there was no effective treatment or drugs for prevention. Deciding to take PrEP felt like an empowering way to protect their health and their community.

So Hurley pushed the doctor, and after the physician did his own research, he agreed to prescribe PrEP.

Hurley got the care they needed, but they had to be the expert in the exam room.

“That’s a big burden,” said Beth Oller, a family medicine physician and board member of GLMA, a national organization of LGBTQ+ and allied health care professionals focused on health equity. “You really want someone you can just go in and talk [to] about your health concerns without feeling like you are having to educate and advocate for yourself at every turn.”

Oller said many queer people have had negative experiences during health care visits.

“I have a lot of patients who had not done preventive care for years because of the medical stigma,” she said.

Billing Headaches

Clearing the access hurdles to HIV prevention medicine was just the beginning. Hurley started receiving a string of bills for PrEP-related care. Blood test: $271.80. Office visit: $263.

Again, Hurley was surprised. They knew — even if the billing office didn’t — that under the Affordable Care Act most private insurance plans and Medicaid expansion programs are required to cover PrEP and ancillary services, like lab tests, as preventive with no cost sharing.

The bills for doctor visits and blood draws piled up.

Hurley would appeal the bill and get a denial almost every time. Then, they would appeal again.

Hurley shared a series of appeal letters for one service, in which the billing office acknowledged that blood work had been initially incorrectly coded as diagnostic. Once that was corrected, Hurley said, the insurer paid for the service.

That might sound quick or easy to resolve, but Hurley said it took “forever to get through the process.” They dealt with at least six incorrect bills over several months. Hurley estimated they spent more than 60 hours contesting the bills.

During that time, Hurley said, the billing department “is continuing to send me emails and bills

that are saying, You're overdue. You're overdue. You're overdue."

Fed up with the hassles, Hurley decided to find a health provider (and billing office) better informed about PrEP. They settled on the AIDS Healthcare Foundation. The care team there was able to discuss the pros and cons of different PrEP regimens and knew how to navigate the formulary for Hurley's insurance.

Hurley hasn't gotten an unexpected bill since.

But siloing sexual health care and PrEP off from primary care hasn't been ideal.

"I have multiple organizations that I have to deal with to get my holistic health dealt with," Hurley said.

A provider doesn't need to be an HIV specialist, an infectious disease expert, or a physician to prescribe PrEP. The Centers for Disease Control and Prevention encourages primary care providers to treat PrEP like other preventive medications.

To avoid some of the headaches Hurley faced, try these tips:

1. Find Out if PrEP Is Right for You

The CDC estimates 2.2 million Americans could benefit from HIV prevention drugs, but just over a quarter of that group have been prescribed them.

"Not enough people know about PrEP, and there are a number of people who know about PrEP but do not realize it's for them," said Jeremiah Johnson, executive director of PrEP4All, an organization dedicated to universal access to HIV prevention and medication.

According to the CDC's clinical guidelines, PrEP can be prescribed as part of a preventive health plan to anyone who's sexually active. It's especially recommended for people who don't use condoms consistently, intravenous drug users who share needles, men who have sex with men, and people in relationships with partners living with HIV or whose HIV status is unclear.

The vast majority of PrEP users are men. There are big race, gender, and geographical disparities in the distribution of HIV and the populations taking the prevention medicine. For example, based on the patterns of new infection in the U.S., a group that would benefit from PrEP is cisgender Black women, whose gender identity aligns with their sex assigned at birth.

2. Don't Assume Your Provider Knows About PrEP

If your doctors aren't well informed, start by educating yourself. There are also clinical guidelines and information you can share with your provider. Check your state or local health department for a how-to guide for prescribing PrEP. For example, the New York State Department of Health AIDS Institute has information for providers.

The CDC also has PrEP guidelines, but many of the agency's websites dealing with LGBTQ+ health are in flux. Under the Trump administration, some HIV/AIDS resources have been taken down from federal websites. Others now have headers saying: "This page does not reflect biological reality and therefore the Administration and this Department rejects it."

3. Get Lab Work In-Network

Johnson said Hurley's experience with billing mistakes is common. "The lab expenses in particular end up being very tricky," Johnson said.

For example, a doctor's office may mistakenly code the lab work required for PrEP as a diagnostic test instead of preventive care. Patients like Hurley can end up with a bill they shouldn't have to pay. If your doctor's office is making mistakes, share the PrEP billing and coding guide from NASTAD, an association of public health officials who administer HIV and hepatitis programs.

Try to get your lab work done in-network. If the lab is out-of-network, Johnson said, it can be difficult to appeal.

If the bills keep coming, appeal them. And if you can't resolve the dispute, Johnson said, file a complaint with the agency that regulates your insurance plan.

4. Look for Ways To Save

There are different kinds of PrEP. There are lower-cost, generic versions of Truvada, for example, sold as emtricitabine/tenofovir disoproxil fumarate, often shortened to FTC/TDF. Newer PrEP drugs Apretude [cabotegravir] and Yeztugo [lenacapavir] have list prices in the thousands of dollars. Check your insurance formulary and ask your doctor to prescribe medicine your plan will cover.

With many health care premiums dramatically increasing and millions at risk of losing Medicaid coverage, many people may go without health insurance this year. Drug manufacturers such as Gilead and ViiV have assistance programs for qualifying patients. If you have to pay out-of-pocket, prescription price comparison websites, like GoodRx, can help you find the pharmacies with the cheapest price.

5. Consider Telehealth

Telehealth is an increasingly popular option if you don't live near an affirming provider or are looking for a more private way to get PrEP. In 2024, roughly 1 in 5 people on PrEP used telemedicine. Online pharmacies like Mistr and Q Care Plus offer PrEP without an in-person appointment, and lab work can be done at home. Some telehealth options have ways to lower the cost if you're uninsured.

Telehealth can also broaden the number of doctors who are ready to prescribe PrEP. And some patients say speaking with a remote provider feels like a safer setting to talk about sexual health.

“They’re in the comfort of their own bedroom or living room but can interface virtually with a provider. It can open up a lot of doors for honesty and trust,” said Alex Sheldon, executive director of GLMA.

6. Seek Out Affirming Care

GLMA created the LGBTQ+ Healthcare Directory, a searchable database of health care providers across the nation who identify as queer-friendly. As Hurley discovered, living in a major metro area is no guarantee your doctor is up to date on LGBTQ+ health care.

Ask locals you trust for recommendations. You might be surprised to find good options nearby.

Health Care Helpline helps you navigate the health system hurdles between you and good care. Send us your tricky question and we may tap a policy sleuth to puzzle it out. Share your story. The crowdsourced project is a joint production of NPR and KFF Health News.

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