PEP: In Case of Emergency

Post-exposure prophylaxis can stop HIV, but only if you and your health care providers know about it.

September 5, 2013 By Casey Halter

When HIV-negative people are exposed to the virus—say, through a condom break, a safer-sex "slip up" or a sexual assault—they can prevent an infection from taking hold if they start a daily regimen of meds called post-exposure prophylaxis, or PEP.

This summer, when a New York man went to a hospital emergency room and requested PEP, he was initially refused the treatment. After a call to activist group ACT UP, he got the meds—and PEP got in national headlines.

PEP is an important prevention tool, not only for those who are negative, but also for HIV-positive people in serodiscordant relationships (i.e., their partners are negative). "We want to make sure we can do everything we can to protect our partners," says Reed Vreeland, communications coordinator for the Sero Project and an active member of ACT UP New York. "If a condom breaks, we want to make sure we can send our partners somewhere they'll get effective treatment immediately that will greatly reduce their chances of becoming HIV positive."

So what's the hold-up with PEP? How accessible is it, where is it, and how can you be proactive about acquiring it?

PEP 101

PEP is a course of treatment that can prevent HIV transmission after a person is potentially exposed to the virus via infected blood, genital secretions or bodily fluids.

Often coined the "HIV morning-after pill," PEP must be started within 72 hours after a person is put at risk. But unlike the one-time Plan B contraception pill, PEP requires taking at least three antiretroviral (ARV) medications daily (sometimes a few times a day) for 28 days. They are the same drugs HIV-positive people take daily to keep the virus from replicating once it has a foothold in the body.

"It takes about five days for HIV to work itself through our bodies and into our bloodstream,"

writes Antonio Urbina, MD, of the Spencer Cox Center for Health and the executive producer of PEP411.com. “Once HIV enters into the bloodstream, a person is infected with HIV and nothing can be done to reverse this infection. PEP works by blocking HIV’s ability to make copies of itself. By doing this, the HIV virus is contained and destroyed by the body before it has a chance to cause infection.”

PEP is not to be confused with pre-exposure prophylaxis, or PrEP, which is when HIV-negative people take a daily course of Truvada (a combo pill of two HIV meds) to lower their risk of infection in case of a future exposure. For more on PrEP, click here.

In 1996, PEP studies showed a 79 percent reduction in the odds of seroconversion for health care workers who experienced a potential occupational exposure, such as a needlestick injury. Since then, oPEP—for occupational exposures—has been standard of care for health care workers.

Activists began demanding PEP for non-occupational exposure—nPEP—for example, if you had unprotected sex. In 2005, the Centers for Disease Control and Prevention (CDC) updated its PEP guidelines, making it standard of care for everyone. The New York State Health Department followed suit in 2008.

Low Awareness and Poor Access

Before people can ask for PEP, they have to know it exists. And therein lies a huge challenge. “There’s a desperate need for education in our nation about what post- and pre-exposure prophylaxis is,” says Bacilio Mendez, a legal observer who actively advocates for PEP availability in New York City. “Nobody knows what to do if you’re exposed to HIV.”

After this summer’s ACT UP protests, the New York City health department agreed to launch a PEP and PrEP information campaign. But public awareness is only part of the challenge—health providers much also be on board.

Ideally, anyone should be able to get PEP from a doctor’s office, hospital emergency room, urgent care clinic or local HIV clinic. But in the real world, most U.S. hospitals lack proper nPEP protocols. A Massachusetts study found that only about 15 percent of hospital emergency rooms had an nPEP protocol. A 2013 survey of Los Angeles-area health care sites found that less than 13 percent had PEP on location and only 3 percent would be willing to provide it to an uninsured person. What’s more, no official nationally representative data exists on nPEP use or availability. Although the CDC did establish a national nPEP surveillance registry in 2008, only 800 voluntary reports have been filed to date.

Jim Eigo of ACT UP New York says they’ve documented four incidents in the last year where people “went to emergency rooms or clinics and were either told no such treatment existed, or were given great delays or turned away entirely because they didn’t have something as trivial as current ID.”

In Chicago, Jim Pickett, director of prevention advocacy and gay men’s health at the AIDS

Foundation of Chicago says he met with several city providers to discuss PEP and found "that people don't know much, but they really want to…and these are the people working in the field!"

But not everyone is a gung-ho supporter of post-exposure treatments. Critics counter that easy access to PEP might encourage unsafe behavior at a high cost to the medical community. Others caution that, because many PEP regimens use older meds that have higher side effects, patients might be unlikely to finish the required doses (obviously, for PEP to work, it has to be taken daily as directed).

Hospital emergency rooms have claimed they have limited amounts of these drugs available and that they often run out a few months into their yearly quota. ERs have been accused of saving PEP for rape victims and occupational exposures instead of the first-come-first-served basis recommended on the CDC's guidelines.

The Post-Exposure Experience

When POZ asked the experts about the best way to get PEP, many advised us to skip the hospital emergency room if possible and go straight to a local clinic or primary care physician for the medications.

The ER is often time-consuming, bureaucratic and impersonal—all dangerous factors when the clock for preventing seroconversion quickly ticks. In addition, emergency rooms will usually only provide a three-day starter pack of meds, along with a prescription referral to a primary care clinic. Basically, you're going to have to go to your doctor ASAP anyway.

But if you're potentially exposed on the weekend or late at night, when many clinics and doctor's offices are closed, the ER could be your only option. In that case, it is important to go in with the right questions and information to ensure timely treatment.

"In most cases, if you need it, there will be someone there to help you figure out how to connect the dots," says Pickett. "But I would show up with a fact sheet, to be sure," he adds. You can print information from Pepnow.org, PEP411.com or aids.gov—or simply have these websites cued up on your smartphone when you see your doc.

At the ER, you will most likely be given a baseline test with a rapid HIV test kit to determine whether or not you are already positive. If you are, PEP treatment won't work. However, if the hospital tells you test kits are not available, you still have the right to preventative treatment. CDC guidelines say you should still be treated with PEP on the assumption that you are not infected.

A full PEP treatment consists of taking several pills daily for four weeks. Missing doses jeopardizes the entire treatment. And for many people, ARVs often cause side effects such as malaise, fatigue, diarrhea, headaches, nausea and vomiting. These may subside as your body adjusts to the drugs. If it seems like too much, ask your doctor about adjusting your treatment or prescribing other meds, such as anti-nausea drugs, to alleviate side effects.

Common therapy combinations for post-exposure prophylaxis include:

- A combination of Sustiva (efavirenz), plus Epivir (lamivudine) or Emtriva (emtricitabine), plus AZT (zidovudine) or Viread (tenofovir). (Note that emtricitabine and tenofovir are often combined as Truvada.)

- A combination of Kaletra (lopinavir/ritonavir), plus Epivir (lamivudine) or Emtriva (emtricitabine) plus AZT (zidovudine)

Whichever you use, store your meds in a cool, dry, sealed place protected from sunlight. Ask your doctor what to do in case you forget a dose (sometimes it's better to take the dose; others, it's better to wait for the next scheduled dose).

After you finish therapy, you will be tested for HIV, and most doctors will also require three-month and six-month checkups to ensure you are in fact negative. Your doctor should also monitor your liver and kidney function for toxicities during and after treatment.

Paying for PEP
Another barrier facing PEP is the high cost of HIV meds.

"Any occupational exposure automatically triggers free 30-day PEP at any medical provider," says Eric Sawyer, founder of UNAIDS and an active HIV advocate. "Yet in New York State and New York City, there are only select few hospitals that have funding to provide PEP for sexual or for exposure through needle sharing." He adds that hospitals often charge high prices for nPEP because of this lack of government support.

If you do have health insurance, co-pays can be upwards of $45 for each prescription depending on the plan. But co-payment cards are available on an application basis through Gilead Sciences (1-877-505-6986) and Merck (1-855-834-3467 or www.isentress.com) if you qualify for assistance.

Without insurance, a full course of treatment can cost between $600 and $1,000 at a hospital emergency room (plus, factor in the ER costs). However, you can get immediate access to the drugs if you are uninsured as long as you apply to Medicaid afterward.

Some pharma companies provide PEP meds for free through "compassionate access programs" or "Patient Assistant Programs" (listed here). Be warned: Dealing with pharmaceutical and government assistance hotlines is often time-consuming and not the best option when the clock is ticking. Some experts recommended requesting preventative drugs pre-emptively from pharmaceutical and insurance access programs; however, the success of this strategy is relatively unknown and untested.

If you are applying to these programs, make sure you have all your information on hand: the date

of exposure, the type of therapy you need, your household income, your insurance information and all personal information.

If you do get prescription assistance, a voucher number will be placed on your prescription and you can go to the pharmacy to get it filled with no out-of-pocket expenses.

For More Information:
PEPnow.org offers a rolling database of clinics and hospitals, submitted by both providers and patients. So far, it includes eight verified hospitals and clinics listed in New York City, two listed in the Northeast, one in the Midwest, three in the South and four out West.

PEP411.com serves the New York area, but the site offers helpful information and videos, in both English and Spanish.

The POZ Health Services Directory, at directory.poz.com, can direct you to local AIDS service organizations. These groups are there to help you!

Want help via phone? These clinics and hotlines are your best bets for providing quick, quality PEP information and treatment:

- Boston: Fenway Community Health Center 617.927.6450 or talkpep.org
- California: San Francisco City Clinic 415.514.4PEP
- Chicago: Howard Brown Health Center 773.388.1600
- New York City: Beth Israel Medical Center 212.420.2000
- U.S.: HIV/AIDS Treatment Information Service 800.HIV.0440
- U.S.: National AIDS Hotline 1.800.342.AIDS
- U.S.: National HIV PEP Registry (for providers only) 1.877.HIV.1PEP
- Washington, DC: Whitman Walker Health 202.745.7000

Editor’s Note: This article has been updated.
