Can HIV Care Click in the Clink?

Stuck behind bars with HIV? Some docs and advocates describe the kind of treatment you can expect.

April 1, 2004 By Carmen Retzlaff

You've got HIV and you're in prison—maybe for a few years, maybe longer, maybe life. Will you get the regular checkups, standard lab and resistance tests, CD4 counts, side-effect management and individualized care you'd demand on the outside?

That depends on where you land. Prison HIV care varies by state and facility—but the American Civil Liberties Union's AIDS/hepatitis information coordinator, Jackie Walker, says few institutions hit treatment highs. Four of the facilities in this story are among the *better* ones—the worst don't want to talk to *POZ*. The fifth, a joint in Alabama, is so bad it's been the subject of a lawsuit.

Most prison health care providers can prescribe almost all FDA-approved HIV meds—at least on paper—though some prisons run out of meds for weeks at a time, interrupting treatment. Meds to treat side effects and opportunistic infections may be more limited. Confidentiality is virtually impossible. Treatment and even testing for hepatitis C is rarely available, despite soaring rates of that virus inside.

You've got your work cut out for you. Advocates and doctors advise bringing all the information you can get to medical visits—you may know more about HIV treatment than the doc. (See "Getting Out Alive" for assistance.)

Nabbing an HIV specialist

In Connecticut, Anne De Groot, MD, contract HIV physician for the Connecticut Correctional HIV Clinic, is one of four specialists who visit, among them, about 300 woman prisoners. In Alabama, there's a specialist for the 200 to 300 HIVers at Limestone—but that person is also the chief medical officer and doc for the 2,000 prisoners in other sections of the joint. In Florida, which has one of the country's highest HIV rates, care varies by location. Ernesto Lamadrid, MD, chief medical officer at Lowell Correctional Institution in central Florida, which houses about 1,900 women, says he tailors first-line treatment to each prisoner. "Their concerns are different, as far as side effects they want to avoid, the number of pills they want to take, how many times they want to take them," he says. But other Florida facilities provide only a regular doc who consults with a specialist by phone. In Texas and California, you might have to "visit" your doctor over a telemedicine system—which relies on lab numbers, charts and computerized records. Jane Murray, MD, of the University of Texas Medical Branch (UTMB) Correctional Managed Care, and med

director for two Houston-area prisons, says, “A lot of decisions for HIV care are based on lab values. You can do a lot without hands on.” But Judy Greenspan, chair of the HIV/Hep C in Prison Committee of California Prison Focus, says telemedicine involves “a doctor looking through a video screen at the prisoner, trying to diagnose and order tests—and there’s a lot lost in the translation.” She also says a specialist is essential: “Up to a year and a half ago, there were women on AZT monotherapy because the doctors didn’t know any better.”

Getting your meds

A few prisons dispense a week’s or month’s worth of meds and let you take them yourself, but most require dragging yourself to pill lines for every dose. In Connecticut, De Groot says, “We provide a week’s supply, prepackaged, unless they’re determined to be Do Not Self-Administer. That’s a joint decision between the provider and the patient, if we’re concerned about adherence or side effects. Then they come to pill line.”

The providers from California, Florida and Texas say most prisoners must go to pill line—in Florida, until they’re close to release. Lamadrid says, “Many people never took medication before. We don’t want to just say, ‘Here’s a couple of brown bags with a bunch of pills, and now you have to take them.’ ” As for Alabama—check out “A Bitter Pill” below.

Treatment issues

“Convincing people to get tested,” De Groot says, is The Big One in Connecticut. “There’s still a lot of stigma, and what becomes known in prison becomes easily known at home.” Hep C coinfection is a huge problem too. “[With] the coexistence of HIV and hep C, trying to hold somebody together with two platelets, because they have really bad end-stage cirrhosis…it’s a horrible way to die.” And she’s seeing more of it.

Lamadrid says some prisoners at Lowell in Florida don’t trust meds. “They say, ‘My cousin was doing well until she started taking HIV medications—then she vomited and had diarrhea,’ and it may take weeks or months to convince the person to be on treatment.” He also cites psychiatric challenges. “[Recently] 54 percent of our people with HIV also had a psychiatric diagnosis. It’s a very complex team effort, [including] drug interactions.”

In Texas, Jane Murray is concerned about adherence (having to go to pill line makes it worse, she says) and post-release care. She sometimes questions starting meds when a prisoner is near release: “Am I going to sort of have a leap of faith that we can try to get him hooked up with something so that when he leaves he doesn’t have to [stop] his medication?”

Joseph Bick, MD, is chief medical officer at California Medical Facility (CMF), which holds about 550 HIVers out of 3,200 prisoners. Released prisoners, he says, must often focus on finding housing and jobs before health care. Mike Mizwa, CEO of AIDS Foundation Houston, which works closely with the Texas DOC, says, “Once the offender hits the walls and is released, continuity of care falls on the shoulders of the community.”

Treatment issues facing HIVers in Limestone mostly stem from the poor quality of care at that institution. Stephen Tabet, MD, who treats prisoners in Washington state correctional facilities, is

the court-appointed medical investigator for a lawsuit against the Alabama Department of Corrections and Naphcare, Inc., Limestone's medical contractor. Limestone's treatment problems, according to Tabet, include this example: A 44-year-old man, positive since 1985, wrote to the medical staff in 1999, saying, "I am having problems with my meds—d4T, ddI and Crixivan. My feet and hands are numb and in pain and I'm throwing up. I am bringing this to your attention because I don't want to take myself off the medications. Maybe there is something that can be done to help these side effects or change the medications. Thank you." The doctor's decision: "Discontinue HIV treatment." The prisoner died in 2001.

Prison bars

Even the best systems bar good care in a variety of ways. In Connecticut, De Groot says, hep C care is limited by " 'rationing by inconvenience.' A number of inmates are excluded because it takes months for the review boards that ration treatment to make a decision."

Staffing—many workers don't last long in the prison setting—bedevils Lamadrid in Florida. "The nurses are the first line to treat side effects and complications," he says. "If [prisoners] have side effects, they tell the pill line. I try to educate the nurses, but it's difficult because of the big turnover with staff." In Limestone, staff shortages result in prisoners providing ad hoc nursing for one another.

Bick cites lockdowns as a hurdle—they can make it hard for prisoners to get to appointments and pill lines.

Then there's money—not enough of it. Owen Murray, MD, medical director for Texas' UTMB Correctional Managed Care, says, "We're not funded to take care of every patient [with] hepatitis C. We brought those concerns to the Texas legislature, and they basically told us to operate within the confines of our current budget." But Greenspan says, "We don't want more funding for unworkable prison medical systems. Prisons can save money by releasing prisoners with life-threatening diseases, the elderly and physically incapacitated on medical parole and compassionate release. We need to rethink the massive rate of incarceration in this country."

Hepatitis Education Prison Project (HEPP) publishes a free monthly report on HIV and hep for clinicians in correctional settings. HEPP Report, Brown Medical School, Providence, RI 02192, 800.748.4336. The American Public Health Association offers "Standards for Health Services in Correctional Institutions" at 301.893.1894 or www.apha.org/media/abc2.htm#prisons.

A Bitter Pill

A prison HIV-med side effect: horrid lines

The Limestone, Alabama facility's morning HIV pill line (200 to 300people) starts at 3 a.m., "because the prison wants it over before breakfast and breakfast over by 6:30 a.m.," says Lisa Zahren, an investigator with the Southern Center for Human Rights, which represents the prisoners in their lawsuit challenging the medical care at Limestone. "People on meds that need to be taken with food aren't given anything to eat. They're not allowed to hold their pills until

breakfast—guards shine a flashlight in your mouth to make sure you've swallowed them."

Stephen Tabet's investigative report called Limestone's med-distribution system "disastrous." He says, "There are no provisions for patients too weak to wait one hour [on line]. One patient with advanced AIDS and a severe brain infection, unable to walk or stand for more than a few minutes, is forced to stand, with a walker, in the pill line."

Got Meds?

All FDA-approved HIV meds are supposedly available in most prisons. But do you really get them? Best-case scenario: In Lowell, Florida, the doc keeps supplies of every HIV med on the premises, "so we have them in stock," to avoid interrupting treatment waiting for the state pharmacy to deliver. In California, it's not such a rosy picture —advocates say prisoners often don't get their meds, or they get the wrong ones. And Limestone, Alabama, ran out of meds at least four times last year. Once, "there was a four-day period when no one got Viracept," an advocate says.

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