Hard Return

Prisoners with HIV, fresh out of jail, find they have many more walls to overcome.

January 1, 2010 By Rachel Rabkin Pechman

In October 2009, after 12 years behind bars, Beverly “Chopper” Henry was released from the Central California Women’s Facility (CCWF)—with $200 and some bus tokens. Living with HIV (and hepatitis C) in prison had been difficult, and getting out offered joy and relief. But Henry’s newfound freedom also presented a range of challenges.

In prison, Henry, now 60, had been among those prisoners who pushed for better care and treatment for their HIV and helped improve prison health care. Because of them, many of the 21,980 HIV-positive prisoners in U.S. jails and prisons now have access to HIV meds and can control their virus while locked up. Unfortunately, research shows that the health of many positive prisoners takes a nosedive once they’re released. A study published online in *PLoS ONE* in September found that only 15 percent of positive prisoners released from the San Francisco County jail system continuously took antiretroviral meds after release. In other words, the majority of former prisoners stopped taking their meds or took them only intermittently—which raised their viral loads and derailed their HIV treatment.

Why, when given a new (re)lease on life, would prisoners neglect their health? It’s simple: Most released prisoners have no medical benefits and scant prison discharge planning help. That deprives them of the services and support they need to secure housing, find a job, get health care benefits and enter drug treatment (if needed)—making it nearly impossible to stay on top of HIV care.

“In prison you have a roof over your head and three meals a day,” says Frederick Altice, MD, of Yale University and an expert on HIV/AIDS care in prison. “Then all of a sudden you’re out and in survival mode, and those basic needs have to be met. So health care and medication go by the wayside.” Add to the mix drug use (rampant in the shelters where many ex-prisoners are forced to reside), and HIV management disappears.

Since her release, Henry has focused on staying healthy. But she found little help through the prison system. “The prison has a transitional case management program, or TCMP,” she says, “but they don’t go out of their way to contact individuals within 90 days of their leaving to help set them up. I happened to hear about TCMP and signed up, but the resources they gave me [were inadequate]. I’m still homeless. And the shelters they sent me to—I wouldn’t put my worst enemy

in there. The world is not very welcoming. I run into one dead end after another." With determination and the ability to speak up for herself, Henry was able to connect with the AIDS Healthcare Foundation (which provides free medical care) and stay with a friend in Los Angeles. But many ex-prisoners don't have a clue where to turn for the services they need.

Jacqueline Walker, AIDS information coordinator for the ACLU's National Prison Project in Washington, DC, lists another obstacle: stigma. "Everything is complicated by the fact that HIV-positive prisoners have a chronic illness that is discriminated against more than other diseases," she says. As a result, positive ex-prisoners often have a particularly hard time finding jobs. After telling potential employers about her criminal record and health status, Misty Rojo, 33, who was released from CCWF in March 2009, says, "I've watched people's faces change during interviews, and I would get weeded out." Rojo did find a landscaping job (with no medical benefits). Her reward? The medical benefits she had received through the county while unemployed were cut off, even though her income could not possibly cover her medical care. "It's like I'm being punished for having employment," she says.

What could be done to help ex-prisoners stay on their meds despite these obstacles? Start before people leave prison, Walker says. "Better prison discharge planning is not going to solve everything, but it will really help. Being hooked into services, having a case manager and having stable housing are key." Nitika Pant Pai, MD, the lead author of the *PLoS ONE* study and a professor at McGill University Health Centre in Montreal, agrees. "Effective case management and keeping track of prisoners whenever they are released into the community," she says, "would really help."

Project Bridge, a small program in Providence, Rhode Island, manages to do that. Caseworkers reach out to HIV-positive prisoners six to three months before their release to help them get Social Security, medical benefits, a photo ID and housing. That way, services are in place by the time prisoners reenter the community. Caseworkers create a clinical plan for each person, accompanying him or her to doctor appointments if needed. "We continue to work with people for up to two years after their release," says Don Laliberte, a former Project Bridge clinical social worker. "We focus on [engaging] the client. If we're driving somewhere and we see someone on the street who [has resisted] our help, we stop and talk to them. That's how we get people to be receptive. Our philosophy is that there is always a chance to begin again."

Inspirational examples like Project Bridge, Altice notes, are few and far between. "Small places that do a great job often have one skilled person who goes above and beyond. In most other places, the systems are archaic, so the transitional care is not good enough," he says. "And as states are going broke, almost all [such] programs are disappearing rapidly." As Pai puts it, "Without funding, you never end up solving the problem. We need policy changes."

For now, it's up to the prisoners to educate—and advocate for—themselves, hunting down the help they need on the outside. "You've got to engage and ask questions of everyone," Henry says. "I didn't learn about HIV by being silent. I learned by taking the initiative to start treating myself. If you take an interest, you can help other people take an interest in helping you."

Out of Prison—and Into Good Health

To control your HIV on the outside, start planning while you're still behind the walls.

Six months before release:

- Find out whether your prison or jail has a discharge worker—a staff member who helps prisoners prepare for release. If so, that person can help with most of the things you need. If there isn't a discharge worker, ask your case manager or the chaplain.Introduce yourself and begin…
- Request help getting a Social Security card, a photo ID and medical benefits. Ask for a referral to a doctor in the community, and for help scheduling an appointment now for after release.
- If you're a veteran, find out if you qualify for any programs.
- If you have no place to live after release, ask whether you qualify for sober housing (to help people—ex-prisoners and others—stay off drugs).
- Write to the ACLU or a local AIDS service organization (ASO) for help with health care, housing or job placement (your case manager can help you find addresses). Some agencies might visit you while you're still in prison.
- Ask your prison doctor for a copy of your medical records. Follow up until you get the files; you may have to sign a release for them. Make sure the records show your HIV status and list all your meds (those you take now and any you've taken before). Your outside doctor will need all that information.
- Request a 30-day supply of your medication to take with you when you're released. This should be given to you just before you leave the institution.
- If there is an HIV peer group (or any other prisoner peer group) in your facility, ask members for tips on getting services outside.

After your release:

- Make sure you keep that first doctor's appointment after you get out. Most doctors have some kind of social service staff in their office. Ask the staff for help finding services.
- Advocate for yourself with the doctor. Describe your situation—that you would like to stay on

your meds but are struggling, for example, with homelessness, trying to stay clean, or whatever issues you face. The doctor may be able to suggest a resource. At the very least, he or she should better understand how to care for you.

- Look up your local department of social services and ask what services might be available to you—then apply for them.
- If you can't find help through these channels, consider seeking a faith-based organization. People there can often point you in the direction of a social service agency if they don't have one within their organization.
- Bring a friend or family member with you to appointments (both doctor and agencies). Having someone else listen along with you can help you understand and remember what's said.
- Contact the National Hire Network, which can refer you to job placement services in your state: hirenetwork.org, 212.243.1313 or 202.544.5478.

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