Women and HIV in US Prisons or Jails [1]

Submitted on May 28, 2019

Note: Since people who are incarcerated in the US do not have access to Internet websites like ours, we hope that outside family members or friends of incarcerated women who could benefit from this material, or prison staff members, will print this fact sheet and share it with women inside. If you would like to request printed copies mailed to a facility, or to someone who works with women inside, please fill out this online order form [2]. If you are an outside advocate for incarcerated women living with HIV, please also see our fact sheet, Advocating for Women Living with HIV in Prisons or Jails in the US [3].

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HIV: The Basics

It is very important to know that HIV is treatable and preventable. If you are living with HIV, there are
dozens of effective drugs available to treat HIV that help people live long, healthy lives — about the same length of life they would have if they did not have HIV.

HIV stands for **human immunodeficiency virus**. HIV is the virus that causes AIDS (**acquired immune deficiency syndrome**). But HIV is not AIDS. AIDS is the most advanced stage of HIV, but you can live with HIV for years with no signs of disease, or just mild symptoms. People who take HIV drugs as prescribed are unlikely to progress to AIDS. Without treatment, in about five to ten years, HIV will wear down the immune system in most people until they develop certain health conditions that indicate AIDS. Then they will have an AIDS diagnosis. However, a person with an AIDS diagnosis can still rebuild their immune system with HIV drugs, and they can still be healthy and live a long life.

If you are HIV-negative, HIV drugs also help you stay that way: If your sexual partner is living with HIV and taking effective HIV drugs (the drugs have suppressed the virus in their body), they cannot transmit HIV to you or anyone else through sex. Using condoms or other barriers, or taking PrEP (pre-exposure prophylaxis — a daily medication for HIV prevention) can also keep people HIV-negative, whether or not the partner's HIV is suppressed.

What keeps the HIV epidemic going are social and economic barriers to getting HIV treatment and care. Misinformation, stigma, and criminalization surrounding HIV continue to make it harder for people with HIV to live their fullest lives. Some of those barriers certainly exist in prisons and jails, but there are also many things you can do to take care of your health while incarcerated (inside, locked up). Learning as much as you possibly can about HIV, and connecting with people who are also living with HIV, are two key steps to staying well.

**If you are in prison or jail, you have the right to HIV care and treatment. The Eighth Amendment of the US Constitution guarantees this right, and the institution you are in is supposed to honor it.**

**How HIV Is Transmitted**

HIV is not easy to transmit. Even in unsanitary conditions, HIV does not spread through touching another person, including their tears, sweat, saliva, feces (poop) or urine (pee). It does not spread through hugging, kissing, shaking hands, or sharing a cell with someone. Sharing food or dishes does not transmit HIV. Neither does coughing or sneezing on someone else. These things are often called "casual contact," and it is not possible to transmit HIV through casual contact.

A person living with HIV who is taking HIV drugs and has an undetectable viral load (not enough HIV in their blood for a test to measure) is **not at risk of transmitting HIV through sex** (vaginal, oral, or anal). This fact is often referred to in the HIV community by the term "Undetectable Equals Untransmittable" ("U=U" for short). Knowing that U=U has reduced a lot of stigma and fear among people living with HIV.

HIV is most often transmitted by people who do not know their status (and therefore are not taking HIV drugs), through sex without condoms or other barriers. HIV is also transmitted through sharing needles to inject drugs or hormones. HIV can also be transmitted to an infant through breastfeeding. The risk of transmitting HIV in these ways is also very low (though not proven to be zero) if the person living with HIV has an undetectable viral load. And while there is basically no risk of HIV transmission through tattooing in a licensed parlor on the outside, prison tattooing with equipment that often cannot be cleaned properly may carry some possible risk of spreading HIV.

Only four body fluids are capable of transmitting HIV:

- Blood
- Semen ("cum" or "pre-cum")
- Vaginal fluids
- Breast milk
Even then, HIV will only be transmitted from one person to another if one of those fluids enters the other person's bloodstream. The virus cannot enter a person's body through unbroken skin. HIV can get into the bloodstream through:

- Mucus membranes ("pink parts") of the body, like the inside of the vagina or anus, gums in the mouth, or the urethra on the tip of the penis
- Punctures, scratches, or rips in the skin (usually from needles)
- Open sores or areas that are bleeding

HIV gets into the bloodstream through activities that involve an entry point like the ones above.

**HIV Testing**

If you have not tested positive for HIV, taking an HIV test can be an important step to protect your health. If you test negative, it is a chance to learn about the many ways HIV can be prevented. If you find out that you are living with HIV, it is an opportunity to find out about ways to stay healthy and live a full life with HIV — including taking HIV drugs.

Depending on where you are incarcerated, you might have been offered an HIV test (or given one without a choice) when you were first processed. If you were not offered an HIV test during intake, you can ask for a test later, if there is any chance you might have acquired HIV (gotten HIV, become HIV-positive) in the months or even years before you were arrested.

It is important to remember that it takes one to three months (and occasionally up to six months) after acquiring HIV for the virus to show up on most HIV tests. This three- to six- month period between getting HIV and producing antibodies (markers in your blood) to HIV is called the "window period." If you believe you were exposed to HIV less than three months before you entered prison or jail, an HIV-negative test result will not be reliable. For an accurate result, it is important to be tested outside the window period.

Victoria Drain and Penni Bullington are two women living with HIV who spoke to journalist and advocate Victoria Law about their very different experiences with HIV testing while incarcerated:

"Victoria Drain doesn't know how long she has been HIV positive. She was never offered an HIV test during the months she spent in an Ohio county jail.

"It was not until she was sentenced and sent to Ohio's prison system in July 2016 that she was screened for HIV. 'Your second morning there, every new offender undergoes a series of blood work, HIV testing not only included, but mandatory,' Drain, a trans woman sentenced to a men's prison, told TheBody.com via letter. 'A couple weeks later, I'm called to medical and received the news of my HIV result.'"

"I tested poz in 2000 at Corcoran,' wrote Penni Bullington in a letter to TheBody.com. Bullington is a trans woman who has spent 28 years in and out of California's prison system. But, she continued, she 'wasn't told or given my test results till the day I paroled from Mule Creek [a different prison] in 2002. So every single person I tattooed, shot dope, had sex with, is now [or] could very well be HIV-positive.'

Bullington had been in various California prisons throughout the 1990s and, both inside and
out, watched many friends fall ill and die from HIV-related complications. Despite their deaths, she said, 'I used to think I would never get it.'"

From "Despite Advances on the Outside, Life for Women With HIV in Prison Remains Risky," [7] by Victoria Law for TheBody. TheBody is an online-only publication, but you can have someone on the outside print and mail a copy for you if you would like to read the full article.

Just Diagnosed? You Are Not Alone.

If you just found out that you are living with HIV, it is normal to feel a range of strong emotions. It is important to allow yourself to feel whatever comes up. It is also important to know that HIV is not a death sentence. It bears repeating over and over again that when people are able to manage the virus with HIV drugs, they can live long, healthy lives with HIV.

Here are a few things to consider doing when you feel ready to cope with living with HIV:

- **Educate yourself about HIV.** Many people living with HIV, including in prison, have said that learning as much as they could about HIV was part of staying as healthy as possible. Prison medical staff may be able to provide you with some information. There are several organizations and publications in the Related Publications section below that you can write to for print copies of health magazines, fact sheets, or booklets. Outside family or friends can also print things from the Internet and mail them to you.

Some people may worry that asking for HIV information will reveal their HIV-positive status to someone — including prison staff who read the mail — before they are ready to share it. If this is a concern, you can write to a lawyer asking them to provide the information for you, since communications with lawyers are private.

- **Building a support network can help you learn how to cope.** Other people in the same prison or jail as you, including medical staff, may be able to refer you to a support group inside, or an outside HIV organization that works with people in the facility you are in. It can be very helpful to join a prison support group if there is one. If not, you can see if it is possible to start one.

It may be possible to find a community or prison advocacy group to help you. The Center for Health Justice is one outside group that operates a free HIV prevention and treatment hotline (213-229-0979), which takes collect calls from prisons Mondays through Fridays, 8 a.m.-3 p.m. Pacific time. It is ideal to be able to find at least one other person who is living with HIV in prison who you can trust to talk to.

- **You may want to take your time in telling others.** You do not have to feel that you have to tell everyone right away. If it is hard to tell family and friends at first, you may want to turn to HIV organizations or groups. In our recent survey, a majority of women reported they disclose first to another person living with HIV, often because it feels safe and free from judgment.
- **If you are religious,** you may find talking to a prison faith leader (chaplain, imam, rabbi, or other religious official) helpful. Even if they do not know much about HIV, they can provide comfort. Like the medical staff, your communications with religious staff are also supposed to be private.

*Part of this section is adapted from "Words to Live By," [8] by a formerly incarcerated person living with HIV, for Prison Health News.*

Waheedah Shabazz-El is a Muslim woman, mother, grandmother, great-grandmother, and a powerful
and celebrated HIV activist based in Philadelphia. Shabazz-El cofounded and is a staff member of Positive Women's Network - USA, a national advocacy network of women living with HIV. Before that time, she went to jail while addicted to crack, and was diagnosed with HIV and given an AIDS diagnosis while inside. She shared some of her experience on The Well Project's A Girl Like Me blog in 2010:

"I'm the person who landed in jail with a bail that was way out of the reach of my family, so I sat for six months (had to remain in jail). I'm the person who took a test for HIV while I sat...whose results came back positive, compounded with an AIDS diagnosis... I'm the person who had made a shambles of her life and decided that death was the only way out. I'm the person who wished for death...but just like all my other wishes that never came true...death never came either. That was seven years ago. But, then they say seven is a lucky number.

...I knew in order to gain acceptance and become empowered over my AIDS diagnosis (like my mentor), I had to seek out the services and support systems that had worked for him. Sounds pretty simple? For me these were the magic bullets.

Today I am a person who no longer uses drugs, a day at a time. I'm a person who gives back what was so freely given to her. I have become a mentor for people just like me. Incarcerated, in recovery from addiction and in recovery from feelings of inadequacy associated with HIV.

Today I am a person for whom HIV is no longer a secret, but in contrast, HIV turned out to be a situation that has brought significant purpose to my life. Today I am the person who no longer wishes for death, but instead I aspire immortality through being a resonating voice for those behind bars, in addiction recovery and women living with HIV/AIDS who haven't found their own voices yet or who choose to speak softly."

From "From the Crack House to the White House? (Not in My Wildest Dreams)," [9] by Waheedah Shabazz-El

See the sections below for even more experiences from currently and formerly incarcerated women (and a few men) that may be helpful to you in advocating for yourself and your health — and in knowing that you are not alone.

**HIV Treatment and Care**

No matter what type of institution you are incarcerated in (federal, state, or county), the Eighth Amendment to the US Constitution applies. It reads: "Excessive bail shall not be required, nor excessive fines imposed, nor cruel and unusual punishments inflicted." According to US courts, this means that you have a right to medical care while you are in jail or prison — including HIV care and HIV drugs.

**HIV Medication Basics**

Even though there is no cure for HIV, nowadays there are many HIV drugs that help keep the virus under control with few to no side effects. Treatment with HIV drugs can improve your quality of life and help you stay healthier longer. National and international treatment guidelines, which healthcare providers all over the world use in providing HIV care, recommend that all people diagnosed with HIV take HIV drugs, even if they have never felt sick due to HIV.

It is very important to take HIV drugs exactly as they are meant to be taken, and not to miss doses. If HIV drugs are not taken regularly on schedule and as they were prescribed (adherence), then the level of HIV drugs in your body may get too low for the drugs to be able to fight HIV effectively.
When a drug can no longer fight HIV, the virus has become "resistant" to that drug. Drug resistance can cause your viral load to rise. As mentioned earlier, if your viral load is undetectable, you cannot transmit the virus. These are just some of the many reasons why challenges or delays getting HIV treatment in prison or jail are so serious.

**Getting Your HIV Drugs**

If you are experiencing delays or other problems getting your HIV drugs on time and the right way, there are several things you can do:

- If you learn the names of prison medical personnel, you can address requests and complaints about missed meds to the appropriate person.
- Grievance systems can be slow. It can be faster to ask your unit staff to call the medical department to retrieve your meds. If the prison won't follow the doctor's orders, you can complain in writing to your treating doctor. Write to the prison warden and medical officers too.
- It's good to store a copy of your prescriptions in your cell or on your person. If you learn the medication schedule and stick to it, you can't be blamed for missed doses.
- A phone call to the prison from someone outside — a family member or friend — asking why you are not getting your meds may produce results.
- If, despite your best attempts, the prison is just too overcrowded or poorly run to deliver your doses, you can consider filing suit. You'll need to show a court that the prison did not provide prescribed medication as required. Medical lawsuits are hard to win, and you first have to go through the prison grievance process (except if you are suing for money damages after release).

Excerpted from "How to Get Your Meds" by Paul Wright, in the first issue of Turn It Up! Staying Strong Inside (Fall 2015/Winter 2016), a health magazine for people in prison. The first issue is available online at the link below, if you are able to get someone on the outside to print and mail it for you. The second issue is available in print if you write to the address below.

**Voices of Women Seeking HIV Treatment**

Different facilities operate differently, and every woman is not going to have the same experience getting HIV drugs and care while incarcerated. Some prisons have good medical staff and offer decent treatment. But others do not.

Several women living with HIV have shared the actions they took to get the treatment they needed — and that it was their right to have. Your experience may be different, but it may help to know that many others have lived with HIV and sought treatment inside.

"Though [Kodi Faircloth] told jail officials about her HIV status and asked for medication, she received none, she said.

"It was only after she entered Mabel Bassett Correctional Center, Oklahoma's largest women's prison, and sent 45 requests for medical care that she was finally able to see a doctor [on Nov. 2, 2015]. ... Even then, it wasn't until mid-November that she finally began receiving medication. ...

"Once a year, Faircloth is brought to a room with a video screen where she 'meets' with the HIV specialist, a practice known as telemedicine. 'She reads our labs by email,' she described. 'The appointment lasts only three to five minutes.' The specialist then instructs the prison's chronic care doctor about any follow-up treatment that Faircloth might need. Then Faircloth is escorted from the room until the next year's visit.

"Faircloth undergoes blood tests every four months, but, she writes, 'Unless we stay on them,
we never get our blood results."

"Christine Johnson already knew her status when she entered the North Carolina Correctional Institution for Women in January 2014. ‘I have been HIV positive for little over 20 years,’ she wrote in a letter to TheBody.com. ‘The virus has been suppressed for almost eight years. I am very open and honest in prison, as well as on the street, about being HIV positive,’ she explained. But that openness comes with a price: Johnson faces shunning, stigma, and violence on a daily basis. ... She's also had her medications, food, and clothing stolen from her, acts which happen not simply because she's in prison but because she's open about her status in prison.

"The stigma and violence largely come from the other incarcerated women, most of whom have little to no knowledge about HIV. There's no easy way to get information, either. Like many prisons, there are no programs or classes about HIV and transmission, leading to fear and ignorance. Johnson believes offering such a class or program would help curb the ignorance, violence, and stigma. 'I believe that when women come in on reception [they] should take classes on how you can catch HIV,' she reflected."

"[Penni] Bullington, who has been transferred to several different facilities since returning to prison in 2004, says that each time she arrives at a new prison, her medications, medically ordered diet, and medical appointments are cancelled. ‘You will wait on a doctor or nurse practitioner to see you within 90 [days] of your arrival,’ she explained. ‘You will see some doctor on a Skype/telemedicine [call] who will dictate if you get to keep any of your [medical] stuff. But generally, you have [already] gotten sick and had to file an emergency 602 appeal to get services.’ (A 602 is a written complaint, or grievance, about prison conditions or practices.)"

From "Despite Advances on the Outside, Life for Women With HIV in Prison Remains Risky." [7] by Victoria Law for TheBody. TheBody is an online-only publication, but you can have someone on the outside print and mail a copy for you if you would like to read the full article.

Advocating for Yourself After Getting HIV Meds

Getting HIV meds by advocating for yourself is a great accomplishment — but the problems may not be over quite yet. Teresa Sullivan is another seasoned HIV advocate in Philadelphia who is formerly incarcerated and now trains people living with HIV who have been released from prison or jail to be advocates and peer educators. Sullivan has also been a co-editor of Prison Health News; she shared one past experience at the pill window, and what she recommends people do if they face obstacles getting their HIV drugs inside.

"When I went to jail in 2005, one of the biggest problems that I had was at the medication window. One day going to get my HIV medications at the window, I looked at the meds in the cup and they were the wrong meds. There was one too many of the same meds for my HIV medications, and one med I never saw before. This was a big problem because I know that taking the wrong dose of my meds would make me sick – and that med that I never saw before in the cup was not the medication that the doctor ordered for me.

"Being told if I did not take the medication in the cup that I would have to go to the hole – that made me very scared, and so I took the medications. Let me say, if I knew what I know today I would have never done that stupid thing, because I got so sick that they had to take me to the ER and I could have died. It is important to know your rights about taking medication while in jail. ..."
"Knowing your rights when it comes to advocating for your medications:

- Before going to the medication window, you should have had a communication with the doctor about what meds you will be taking. Secondly, you should ask the doctor if they have a med chart for you to look at so you know what your meds are and what they look like. THIS IS YOUR RIGHT.
- If, for some reason, when you go to the medication window the meds don't look right to you, ask the nurse to please check the doctor's order again. THIS IS YOUR RIGHT.
- Because sometimes the nurses may be in a rush and they can make mistakes, these mistakes can make you sick or could kill you if you do not advocate about your meds. THIS IS YOUR RIGHT.
- Too often, [people] don't know their meds when going to the med window, and too often they don't ask questions about what they are taking, because they don't know that they have the right to advocate for themselves. If the nurse does not answer your question, then ask to talk to the sergeant on duty. THIS IS YOUR RIGHT.
- Once you're in jail, medical staff supply you with your regular prescription medications. Usually the jail staff dispenses only medication from its infirmary, since it won't trust that what you brought in is the real thing. Sometimes its practitioners try to substitute a similar medication for what you normally use. If this is a problem, have your doctor specify 'no substitutions' in his or her letter. Often, there is a big lag of 24 hours or more between getting arrested and first receiving regular doses of medication."

Excerpted from "Getting Out Alive," [10] by Teresa Sullivan for Prison Health News. You can write to them for copies of their publication at the address below.

Getting the Best Care You Can

In addition to the suggestions above, these tips are just a few overall steps that may help you get better care while in prison or jail. They are summarized from a longer article written by Brian Carmichael, a longtime prison HIV activist who has been living with HIV for more than 20 years, and in prison for more than half of his life, in the second issue of Turn It Up! Staying Strong Inside.

1. **Educate yourself.** Learn about your medical conditions, including the best available treatments and medications. Reach out to knowledgeable peers and local organizations. Know your stuff and be your own advocate.
2. **Keep a journal.** In a writing tablet, calendar, or some blank typing paper from the Law Library, create your own little medical file, keeping track of everything related to your health. Entries don't have to be long and drawn out, but enough for you to keep track and provide accurate information to your provider when making decisions about your treatment.
3. **Be polite, respectful, and appreciative.** Just saying "Please" and "Thank You" goes a long way. Even if you're beefing with a doctor or nurse, avoid personal attacks and insults, as much as their attitudes or actions may lead you to feel disrespected. When you file a grievance, or a lawsuit, your position will always be on stronger ground if you can say, "I have always treated the medical staff at this institution with courtesy and respect."
4. **Be organized when you go to Sick Call and doctor's appointments.** Have a list of your issues, prioritized. That way you won't forget something and have to wait another three or four months (or more) until your next doctor's appointment.
5. **Always turn in prescription renewal requests five days in advance.** The pharmacy will have plenty of time to fill your prescription, and if you don't get your meds by the time your old 'script runs out, you can ask a C/O to call. When the pharmacy asks, "Why did you wait until the last minute to renew your meds?" you can say, "Actually, I submitted my request five days ago, and it's important I not miss any doses of this medication."
Planning for Release

If you will leave prison or jail soon, it is important to make a plan for continuing your treatment when you return to the community. You can ask for a meeting with a social worker or discharge planner quite a while before you think you will be discharged. That person may help you to:

- Get (back) on Medicaid or another insurance immediately after your discharge. You may be able to apply for this while you are still in prison or jail.
- Get in touch with a community HIV organization. That organization can help you get the care you need and may be able to arrange for other services, as well.
- Make the first HIV clinic appointment after you are discharged. It is important to have that appointment in place before you leave prison or jail to make sure you do not miss any medication doses.
- Plan for housing and transportation to that first appointment

A good idea is to try to get the prison medical staff to mail your medical records to your new HIV care provider, once you have that first medical appointment set up. If they are not able to do that, you can see if they can give you a complete written summary of your medical care to share with your new provider on the outside. Even if the medical staff is not able to do either of these things, if you have been keeping a health journal as Brian Carmichael suggests above, you can bring that information to your first appointment.

You may also be able to get a supply of HIV drugs to tide you over until that first appointment. You can ask the medical staff if you can get a 30-day supply, and remind them if you don't hear back for a while. It may be easier to get the necessary amount of medication, if you can show a fixed appointment and a plan for getting there.

Even with all the other things you likely have to take care of when you are being released, it is important to make your health a priority, and do your best to attend that first clinic appointment. Staying connected to care will not only help you protect your HIV health, but your clinic can help you to get (or point you to a community organization where you can get) some of these resources to keep you healthier and safer overall:

- Assistance with housing and/or food
- Help covering transportation costs
- Getting mental health treatment or counseling, if necessary
- Any other help they can provide, such as support groups or referrals to other services

Part of this section is adapted from "Preparing for Your HIV Care on the Outside," from a 2016 discharge planning manual, for Prison Health News. You can write to them for copies at the address below.

The Bottom Line

"We've heard all the phrases, like 'A closed mouth don't get fed,'" writes Fatima Malika Shabazz, a trans woman who has fought for another kind of health care — gender-affirming treatment and surgeries — while incarcerated. "Well, that is true. If you don't speak, no one will know you're there."

There are many ways to live a full, healthy life with HIV. Some steps to take to get there while in prison or jail include learning as much as possible about HIV, asking questions of those who have useful knowledge about living with HIV, knowing your rights, and being your own best advocate.
Some of the currently and formerly incarcerated writers who have contributed their experiences, excerpted here, are examples of how people have "opened their mouths" to get the care they deserve.

**Related Publications**

*These resources are accessible to people in prison or jail*

**Please note:** None of these organizations or publications offer legal help.

To ask questions, or to order free single or bulk copies of the second issue of *Turn It Up! Staying Strong Inside* [13], write to:

**The Sero Project**
P.O. Box 1233
Milford, PA 18337
info@SeroProject.com

To order copies of *Prison Health News* [14], write to:

**Prison Health News**
c/o Books Through Bars
P.O. Box 54458
4722 Baltimore Avenue
Philadelphia, PA 19143
prisonhealthnews@gmail.com [15]
215-326-9431

**Center for Health Justice** [16]

Free HIV prevention & treatment hotline; takes collect calls from prison Mon.-Fri., 8 a.m.-3 p.m.

Prison Hotline: 213-229-0979 (collect)

You can reach the organization via mail at:

900 Avila St., #301
Los Angeles, CA 90012
213-229-0985

To receive a free subscription (must renew each year) to *POZ Magazine* [17], a health, lifestyle, and advocacy publication for people living with/affected by HIV, write to:

**POZ Magazine**
212 West 35th Street, 8th Floor
New York, NY 10001

To get copies of *Positively Aware* [18], an HIV treatment magazine ($30 suggested donation; free to people living with HIV who cannot afford it), write to:

**Positively Aware**
Attn: Distribution Manager
5527 North Broadway Street
Chicago, IL 60640

*Special thanks to Laura Whitehorn, prison activist, former political prisoner, and past senior editor of POZ Magazine, for her review of this fact sheet.*