# HIV/AIDS Course

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# **Approvals**

This course is recognized by the California Board of Behavioral Sciences.

This program is Approved by the National Association of Social Workers (Approval # 886463870-8049) for 7 continuing education contact hours.

This program is approved for 7 continuing education hours by:

The California Board of Registered Nursing # CEP 14462 The National Association of Social Workers (NASW) # 886463870-8049 The Florida Board of Clinical Social Work, Marriage and Family Therapy and Mental Health Counseling #50-14000 Texas Board of Examiners of Marriage and Family Therapists # 628 Texas State Board of Examiners of Professional Counselors #1646 The Texas Board of Social Worker Examiners # 5547 The National Board for Certified Counselors (NBCC) # 6412

# **COURSE OBJECTIVES**

After completing this training the professional healthcare provider will be able to:

- 1. Explain to clients the HIV/AIDS disease
- 2. Discuss a brief history of the epidemic
- 3. Identify the physiological characteristics of HIV/AIDS
- 4. Explain the psychosocial issues seropositive patients present
- 5. Assess and provide psychosocial services for people living with HIV and AIDS

6. Distinguish between typical myths and misconceptions versus knowledge and facts about HIV/AIDS

7. Recognize and integrate into treatment the changing biopsychosocial impact of AIDS as people live longer due to increased knowledge and improved treatment

# I. INTRODUCTION

In 1981 the first known case of HIV/AIDS was diagnosed in the United States. Since that time, our country has gone through many phases of fear, misinformation, prejudice, sorrow, anger, compassion, apathy, and hope. HIV is the cause of one of humanity's deadliest and most persistent epidemics.

Discussing HIV may lead to debates as moral, physical, social and political biases are revealed. Along with the debates are the millions of people who have been diagnosed with HIV/AIDS, many who have died from the effects of the virus, and many others who still live with it. Having a correct and thorough understanding of HIV/AIDS is critical in offering effective counseling and support to clients who are dealing with their diagnosis.

Chapters II-VII of this course are entirely derived and adapted from the U.S. government site hiv.gov along with supplementation from the Centers for Disease Control and Prevention. Chapter VIII will focus on the counseling aspects of dealing with the clientele dealing with HIV/AIDS.

# **Chapter II. Overview**

# A. About HIV & AIDS 1. What Are HIV and AIDS?

### What Is HIV?

HIV (*human immunodeficiency virus*) is a virus that attacks cells that help the body fight infection, making a person more vulnerable to other infections and diseases. It is spread by contact with certain bodily fluids of a person with HIV, most commonly during unprotected sex (sex without a condom or HIV medicine to prevent or treat HIV), or through sharing injection drug equipment.

If left untreated, HIV can lead to the disease AIDS (*acquired immunodeficiency syndrome*).

The human body can't get rid of HIV and no effective HIV cure exists. So, once you have HIV, you have it for life.

However, by taking HIV medicine (called antiretroviral therapy or ART), people with HIV can live long and healthy lives and <u>prevent transmitting HIV</u> to their sexual partners. In addition, there are effective methods to prevent getting HIV through sex or drug use, including <u>pre-exposure prophylaxis (PrEP)</u> and <u>post-exposure prophylaxis (PEP)</u>.

First identified in 1981, HIV is the cause of one of humanity's deadliest and most persistent epidemics.

#### What Is AIDS?

AIDS is the late <u>stage of HIV infection</u> that occurs when the body's immune system is badly damaged because of the virus.

In the U.S., most people with HIV do not develop AIDS because taking HIV medicine every day as prescribed stops the progression of the disease.

A person with HIV is considered to have progressed to AIDS when:

- the number of their CD4 cells falls below 200 cells per cubic millimeter of blood (200 cells/mm3). (In someone with a healthy immune system, CD4 counts are between 500 and 1,600 cells/mm3.) OR
- they develop one or more <u>opportunistic infections</u> regardless of their CD4 count.

Without HIV medicine, people with AIDS typically survive about 3 years. Once someone has a dangerous opportunistic illness, life expectancy without treatment falls to about 1 year. HIV medicine can still help people at this stage of HIV infection, and it can even be lifesaving. But people who start ART soon after they get HIV experience more benefits—that's why HIV testing is so important.

### **How Do I Know If I Have HIV?**

**The only way to know for sure if you have HIV is to get tested**. Testing is relatively simple. You can ask your health care provider for an HIV test. Many medical clinics, substance abuse programs, community health centers, and hospitals offer them too. You can also buy a home testing kit at a pharmacy or online.

**Content Source:** <u>HIV.gov</u> **Date last updated:** June 17, 2019

https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids

# 2. How Is HIV Transmitted?

### How Do You Get or Transmit HIV?

You can only get HIV by coming into direct contact with certain body fluids from a person with HIV who has a detectable viral load. These fluids are:

- Blood
- Semen (cum) and pre-seminal fluid
- Rectal fluids
- Vaginal fluids
- Breast milk

For transmission to occur, the HIV in these fluids must get into the bloodstream of an HIV-negative person through a mucous membrane (found in the rectum, vagina, mouth, or tip of the penis); open cuts or sores; or by direct injection.

People with HIV who take HIV medicine daily as prescribed and get and keep an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIV-negative partners.

### **How Is HIV Spread from Person to Person?**

HIV can only be spread through specific activities. In the United States, the most common ways are:

- Having vaginal or anal sex with someone who has HIV without using a condom or taking medicines to prevent or treat HIV. Anal sex is riskier than vaginal sex.
- Sharing injection drug equipment ("works"), such as needles, with someone who has HIV.

Less common ways are:

- From mother to child during pregnancy, birth, or breastfeeding. However, the use of HIV medicines and other strategies have helped <u>lower the risk of</u> <u>mother-to-child transmission of HIV</u> to 1% or less in the United States.
- **Getting stuck with an HIV-contaminated needle** or other sharp object. This is a risk mainly for <u>health care workers</u>. The risk is very low.

HIV is spread only in extremely rare cases by:

- **Having oral sex**. But in general, the chance that an HIV-negative person will get HIV from <u>oral sex</u> with an HIV-positive partner is extremely low.
- Receiving blood transfusions, blood products, or organ/tissue transplants that are contaminated with HIV. The risk is extremely small these days because of rigorous testing of the U.S. blood supply and donated organs and tissues.
- **Being bitten by a person with HIV.** Each of the very small number of documented cases has involved severe trauma with extensive tissue damage and the presence of blood. There is no risk of transmission if the skin is not broken.
- Contact between broken skin, wounds, or mucous membranes and HIVinfected blood or blood-contaminated body fluids.
- Deep, open-mouth kissing if both partners have sores or bleeding gums and blood from the HIV-positive partner gets into the bloodstream of the HIV-negative partner. HIV is not spread through saliva.

• Eating food that has been pre-chewed by a person with HIV. The contamination occurs when infected blood from a caregiver's mouth mixes with food while chewing. The only known cases are among infants.

# **Does HIV Viral Load Affect Getting or Transmitting HIV?**

Yes. Viral load is the amount of HIV in the blood of someone who has HIV. Taking HIV medicine (called antiretroviral therapy or ART) daily as prescribed can make the viral load very low—so low that a test can't detect it (this is called an undetectable viral load).

People with HIV who take HIV medicine daily as prescribed and get and keep an undetectable viral load have effectively no risk of transmitting HIV to an HIV-negative partner through sex.

HIV medicine is a powerful tool for preventing sexual transmission of HIV. But it works only as long as the HIV-positive partner gets and keeps an undetectable viral load. Not everyone taking HIV medicine has an undetectable viral load. To stay undetectable, people with HIV must take HIV medicine every day as prescribed and visit their healthcare provider regularly to get a viral load test.

### Ways HIV Cannot Be Spread

HIV is not spread by:

- Air or water
- Mosquitoes, ticks or other insects
- Saliva, tears, or sweat that is not mixed with the blood of a person with HIV
- Shaking hands; hugging; sharing toilets; sharing dishes, silverware, or drinking glasses; or engaging in closed-mouth or "social" kissing with a person with HIV
- Drinking fountains
- Other sexual activities that don't involve the exchange of body fluids (for example, touching).

HIV can't be passed through healthy, unbroken skin.

### How Do You Get AIDS?

You can't "catch" AIDS.

AIDS is the most advanced stage of HIV infection. If you have HIV and you are not on HIV treatment, eventually your body's immune system will weaken and you will progress to AIDS.

People with AIDS have such badly damaged immune systems that they get a number of severe illnesses, called opportunistic infections.

People who are HIV-negative can prevent getting HIV by using PrEP (pre-exposure prophylaxis). Postexposure prophylaxis (PEP) is a way to prevent HIV infection after a recent possible exposure to the virus. There are other ways to prevent getting or transmitting HIV through injection drug use and sexual activity.

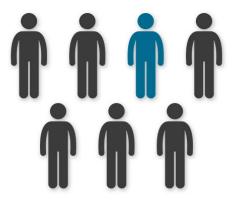
**Content Source:** <u>HIV.gov</u> **Date last updated:** June 24, 2019 <u>https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/how-is-hiv-transmitted</u>

# 3. Who Is at Risk for HIV?

HIV can affect anyone regardless of sexual orientation, race, ethnicity, gender or age. However, certain groups are at higher risk for HIV and merit special consideration because of particular risk factors.

### Is the Risk of HIV Different for Different People?

1 in 7 living with HIV



are **unaware** of their infection.

Some groups of people in the United States are more likely to get HIV than others because of many factors, including the status of their sex partners, their risk behaviors, and where they live.

When you live in a community where many people have HIV infection, the chances of having sex or sharing needles or other injection equipment with someone who has HIV are higher. You can use CDC's HIV, STD, hepatitis, and tuberculosis Atlas Plus to see the percentage of people with HIV ("prevalence") in different US communities. Within any community, the prevalence of HIV can vary among different populations.

Gay and bisexual men have the largest number of new diagnoses in the United States. Blacks/African Americans and Hispanics/Latinos are disproportionately affected by HIV compared to other racial and ethnic groups. Also, transgender women who have sex with men are among the groups at highest risk for HIV infection, and injection drug users remain at significant risk for getting HIV.

Risky behaviors, like having anal or vaginal sex without using a condom or taking medicines to prevent or treat HIV, and sharing needles or syringes play a big role in HIV transmission. Anal sex is the highest-risk sexual behavior. If you don't have HIV, being a receptive partner (or bottom) for anal sex is the highest-risk sexual activity for getting HIV. If you do have HIV, being the insertive partner (or top) for anal sex is the highest-risk sexual activity for getting HIV.

But there are more tools available today to prevent HIV than ever before. Choosing less risky sexual behaviors, taking medicines to prevent and treat HIV, and using condoms with lubricants are all highly effective ways to reduce the risk of getting or transmitting HIV. Learn more about these and other strategies to prevent HIV.

#### Learn More About Groups at Risk for HIV

For more information about the risk for different groups of people, see U.S. Statistics, Impact on Racial and Ethnic Minorities, and CDC's HIV by Geographical Distribution. For more information about groups at risk for HIV, visit CDC's Groups at Risk page.

Content Source: <u>HIV.gov</u> Date last updated: May 15, 2017

https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/who-is-at-risk-for-hiv

# 1. Symptoms of HIV

### How Can You Tell If You Have HIV?

The only way to know for sure if you have HIV is to get tested. You can't rely on symptoms to tell whether you have HIV.

Knowing your HIV status gives you powerful information so you can take steps to keep yourself and your partner(s) healthy:

- **If you test positive**, you can take medicine to treat HIV. People with HIV who take HIV medicine daily as prescribed can live a long and healthy life and prevent transmission to others. Without HIV medicine (called antiretroviral therapy or ART), the virus replicates in the body and damages the immune system. This is why people need to start treatment as soon as possible after testing positive.
- If you test negative, there are <u>several ways</u> to prevent getting HIV.
- **If you are pregnant**, you should be tested for HIV so that you can begin treatment if you're HIV-positive. If an HIV-positive woman is treated for HIV early in her pregnancy, the risk of transmitting HIV to her baby can be very low.

Use the <u>HIV Services Locator</u> to find an HIV testing site near you.

### What Are the Symptoms of HIV?

There are several symptoms of HIV. Not everyone will have the same symptoms. It depends on the person and what stage of the disease they are in.

Below are the three stages of HIV and some of the symptoms people may experience.

Stage 1: Acute HIV Infection

Within 2 to 4 weeks after infection with HIV, about two-thirds of people will have a flulike illness. This is the body's natural response to HIV infection.

Flu-like symptoms can include:

- Fever
- Chills
- Rash
- Night sweats

- Muscle aches
- Sore throat
- Fatigue
- Swollen lymph nodes
- Mouth ulcers

These symptoms can last anywhere from a few days to several weeks. But some people do not have any symptoms at all during this early stage of HIV.

Don't assume you have HIV just because you have any of these symptoms—they can be similar to those caused by other illnesses. But if you think you may have been exposed to HIV, get an HIV test.

- **Request an HIV test for recent infection**—Most HIV tests detect antibodies (proteins your body makes as a reaction to HIV), not HIV itself. But it can take a few weeks after you're infected for your body to produce them. There are other <u>types of tests</u> that can detect HIV infection sooner. Tell your doctor or clinic if you think you were recently exposed to HIV, and ask if their tests can detect early infection.
- Know your status—After you get tested, be sure to learn your test results. If you're HIV-positive, see a doctor as soon as possible so you can start treatment with HIV medicine. And be aware: when you are in the early stage of infection, you are at very high risk of transmitting HIV to others. It is important to take steps to reduce your risk of transmission. If you are HIV-negative, there are prevention options like pre-exposure prophylaxis (PrEP) that can help you stay negative.

### Stage 2: Clinical Latency

In this stage, the virus still multiplies, but at very low levels. People in this stage may not feel sick or have any symptoms. This stage is also called chronic HIV infection.

Without HIV treatment, people can stay in this stage for 10 or 15 years, but some move through this stage faster.

If you take HIV treatment every day, exactly as prescribed and get and keep an undetectable viral load, you can protect your health and prevent transmission to others. But if your viral load is detectable, you can transmit HIV during this stage, even when you have no symptoms. It's important to see your health care provider regularly to get your level checked.

### Stage 3: AIDS

If you have HIV and you are not on HIV treatment, eventually the virus will weaken your body's immune system and you will progress to AIDS (*acquired immunodeficiency syndrome*). This is the late stage of HIV infection.

Symptoms of AIDS can include:

- Rapid weight loss
- Recurring fever or profuse night sweats
- Extreme and unexplained tiredness
- Prolonged swelling of the lymph glands in the armpits, groin, or neck
- Diarrhea that lasts for more than a week
- Sores of the mouth, anus, or genitals
- Pneumonia
- Red, brown, pink, or purplish blotches on or under the skin or inside the mouth, nose, or eyelids
- Memory loss, depression, and other neurologic disorders

Each of these symptoms can also be related to other illnesses. The only way to know for sure if you have HIV is to get tested.

Many of the severe symptoms and illnesses of HIV disease come from the <u>opportunistic infections</u> that occur because your body's immune system has been damaged. See your health care provider if you are experiencing any of these <u>sym</u>ptoms.

**Content Source:** <u>HIV.gov</u> **Date last updated:** June 21, 2019

https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/symptoms-of-hiv

# **Chapter II. Overview**

B. Data & Trends 1. U.S. Statistics

### Fast Facts

Approximately 1.1 million people in the U.S. are living with HIV today. About 15 percent of them (1 in 7) are unaware they are infected.

An estimated 38,700 Americans became newly infected with HIV in 2016.

Gay, bisexual, and other men who have sex with men bear the greatest burden by risk group, representing an estimated 26,000 of new HIV infections per year.

- In 2017, 38,739 people received an HIV diagnosis in the U.S. and 6 dependent areas
- The annual number of new HIV diagnoses in the U.S. remained stable from 2012 to 2016.
- HIV diagnoses are not evenly distributed across states and regions. Of the 38,739 new HIV diagnoses in the U.S in 2017, 19,968 (52%) were in the South.

### **Estimated New HIV Infections**

New HIV infections ("HIV incidence") refers to the estimated number of people who are newly infected with HIV during a year, which is different from the number of people *diagnosed* with HIV during a year. (Some people may have HIV but not know it.)

According to the latest estimates from the <u>Centers for Disease Control and</u> <u>Prevention</u> (CDC):

Approximately 38,700 people became newly infected with HIV in the United States in 2016. After about 5 years of substantial declines, the number of annual HIV infections began to level off in 2013, to about 39,000 infections per year.

CDC estimates that the decline in HIV infections has plateaued because effective HIV prevention and treatment are not adequately reaching those who could most benefit from them. These gaps remain particularly troublesome in rural areas and in the South and among disproportionately affected populations like blacks/African Americans<sup>a</sup> and Hispanics/Latinos<sup>b</sup>.

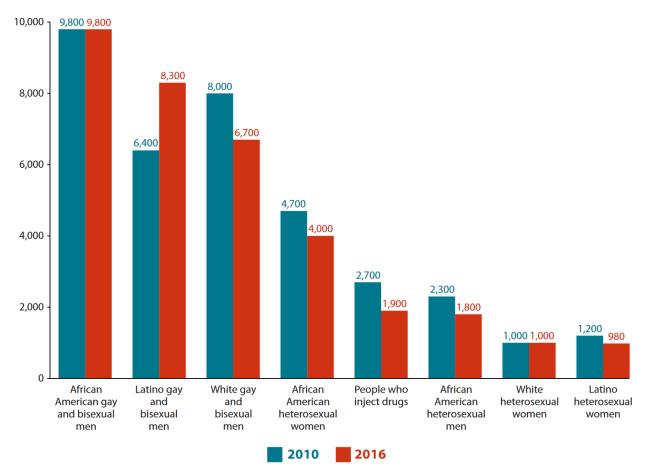
**By age group**, between 2010-2016, the annual number of HIV infections decreased among persons aged 13–24 and 45–54 but increased among persons aged 25–34. The number of infections remained stable among persons aged 33-44 and ≥55 years.

**By race/ethnicity**, between 2010-2016, the annual number of HIV infections decreased among blacks/African Americans, whites, and persons of multiple races and remained stable for Asians and Hispanics/Latinos.

**By sex**, between 2010-2016, the annual number of new HIV infections decreased among females but remained stable among males.

**By HIV transmission category**, between 2010-2016, the annual number of HIV infections decreased among male and female adults and adolescents with infection attributed to injection drug use, and among females with infection attributed to heterosexual contact. The annual number of infections remained stable overall among males with infection attributed to male-to-male sexual contact, among males with infection attributed to male-to-male sexual contact and injection drug use, and among males and females with infection attributed to injection drug use, and there were differences by race/ethnicity and transmission group.

#### New HIV Infections by Race and Transmission Group, U.S. 2010 vs. 2016:



*Source: CDC, HIV Incidence: Estimated Annual Infections in the U.S., 2010-2016, Feb. 2019.* 

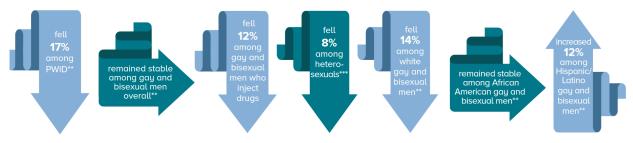
### **HIV Diagnoses**

HIV diagnoses refers to the number of people who have received an HIV diagnosis during a year, regardless of when they were infected. (Some people can live with HIV for years before they are diagnosed; others are diagnosed soon after infection.)

According to the <u>Centers for Disease Control and Prevention</u> (CDC):

In 2017, 38,739 people received an HIV diagnosis in the U.S. The annual number of new HIV diagnoses remained stable between 2012 and 2016 in the U.S. and dependent areas.<sup>c</sup> However, annual new diagnoses have increased among some groups.

#### HIV Diagnoses in the U.S. and Dependent Areas, 2012-2016



Source: CDC, HIV in the United States and Dependent Areas, Jan. 2019. **Gay and bisexual men**<sup>d</sup> are the population most affected by HIV. In 2017:

- Gay and bisexual men accounted for 66% (25,748) of all HIV diagnoses and 82% of HIV diagnoses among males.<sup>e</sup>
- Black/African American gay and bisexual men accounted for the largest number of HIV diagnoses (9,807), followed by Hispanic/Latinos (7,436) and whites (6,982).

Among all gay and bisexual men, HIV diagnoses remained stable from 2012 to 2016, but trends varied by race/ethnicity:

- HIV diagnoses among white gay and bisexual men decreased 14%.
- HIV diagnoses among African American gay and bisexual men remained stable.
- HIV diagnoses among Hispanics/Latino gay and bisexual men increased 12%.

**Heterosexuals and people who inject drugs** also continue to be affected by HIV. In 2017:

- Heterosexuals accounted for 24% of HIV diagnoses.<sup>f</sup>
- Heterosexual men accounted for 7% (2,829) of HIV diagnoses.
- Heterosexual women accounted for 16% (6,341) of HIV diagnoses.
- People who inject drugs accounted for 6% of HIV diagnoses.

From 2012 to 2016:

- HIV diagnoses among heterosexual women decreased 8%.
- HIV diagnoses among heterosexual men decreased 9%.
- HIV diagnoses among people who inject drugs decreased 17%

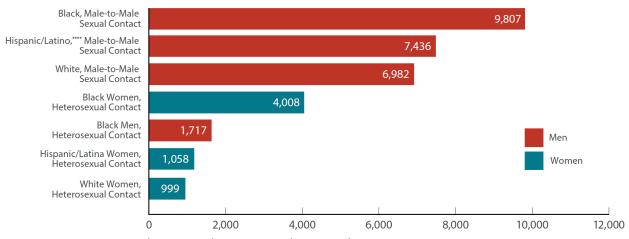
By race/ethnicity, **African Americans** and **Hispanics/Latinos** are disproportionately affected by HIV. In 2017:

- African Americans accounted for 43% (16,694) of HIV diagnoses and 13% of the population.
- Hispanics/Latinos accounted for 26% (9,908) of HIV diagnoses and 18% of the population.

From 2012 to 2016:

- HIV diagnoses among African Americans decreased 5%.
- HIV diagnoses among Hispanics/Latinos remained stable.
- HIV diagnoses among whites decreased 8%.

# New HIV Diagnoses in the U.S. and Dependent Areas for the Most-Affected Subpopulations, 2017:



*Source: CDC, HIV in the United States and Dependent Areas, Jan. 2019.* In the U.S., HIV diagnoses are not evenly distributed across states and regions.<sup>g</sup> In 2017, the South accounted for more than half (52%) of the new HIV diagnoses in the U.S., followed by the West (19%), the Northeast (16%), and the Midwest (13%). U.S. dependent areas made up 1% of new HIV diagnoses. Most infections are now highly concentrated in certain geographic hotspots. More than 50 percent of new HIV diagnoses in 2016 and 2017 occurred in 48 counties, Washington, D.C., and San Juan, Puerto Rico.

### Living with HIV

In all 50 states and the District of Columbia:

• An estimated 1,122,900 adults and adolescents were living with HIV in the U.S. at the end of 2015.

- Of those, about 14% (or 1 in 7) had not received a diagnosis, so were unaware of their infection.
- Young people were the most likely to be unaware of their infection. In 2015, among people aged 13-24 who were living with HIV, an estimated 51% didn't know.
- In 2015, among all adults and adolescents living with HIV (diagnosed and undiagnosed),
  - 63% received some HIV medical care,
  - 49% were retained in continuous HIV care, and
  - 51% had achieved viral suppression (having a very low level of the virus). A suppressed viral load protects the health of a person living with HIV, preventing disease progression. There is also a major prevention benefit. A person living with HIV who takes HIV medicine as daily prescribed and gets and stays virally suppressed can stay healthy and has effectively no risk of sexually transmitting HIV to HIV-negative partners.

### **AIDS Diagnoses and Deaths**

In 2017, 17,803 people in the U.S. and 6 dependent areas received a stage 3 (AIDS) diagnosis.

In 2016, there were 15,807 deaths among people with diagnosed HIV in the United States. Nearly half (47%) of these deaths were in the South; 3,630 (23%) were in the Northeast; 2,604 (16%) were in the West; 1,720 (11%) were in the Midwest; and 379 (2%) were in the U.S. dependent areas. These deaths may be due to any cause.

### The 'Ending the HIV Epidemic' Initiative

<u>Ending the HIV Epidemic: A Plan for America</u>, announced by the President in his State of the Union address on February 5, 2019, is a bold approach to eliminate new HIV infections in our nation. It is built upon the following key strategies:

- **Diagnosing** all individuals with HIV as early as possible after infection.
- **Treating** HIV rapidly and effectively after diagnosis to achieve sustained viral suppression.
- **Protecting** individuals at risk for HIV using proven prevention approaches.
- **Responding** rapidly to detect and respond to growing HIV clusters and prevent new infections.

The proposed initiative is designed to rapidly increase use of these strategies in the 48 counties with the highest HIV burden, as well as in Washington, D.C.; San Juan, Puerto

Rico; and seven states with a disproportionate rural HIV burden. The goal is to reduce new HIV infections by 90 percent over 10 years.

#### Notes

<sup>a</sup> Referred to as *African American* in this fact sheet.

<sup>b</sup> Hispanics/Latinos can be of any race.

<sup>c</sup> Unless otherwise noted, the term United States (U.S.) includes the 50 states, the District of Columbia, and the 6 dependent areas of American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the U.S. Virgin Islands.

<sup>d</sup> These numbers include only diagnoses attributed to male-to-male sexual contact, not those attributed to injection drug use and male-to-male sexual contact.

<sup>e</sup> This does not include gay and bisexual men who reported injection drug use. <u>CDC's</u> <u>HIV surveillance fact sheet</u> provides more information about how CDC classifies the transmission category for HIV cases.

<sup>f</sup> This does not include heterosexuals who reported injection drug use.

<sup>g</sup> This page uses the regions defined by the U.S. Census Bureau and used in CDC's National HIV Surveillance System:

Northeast: CT, ME, MA, NH, NJ, NY, PA, RI, VT

Midwest: IL, IN, IA, KS, MI, MN, MO, NE, ND, OH, SD, WI

South: AL, AR, DE, DC, FL, GA, KY, LA, MD, MS, NC, OK, SC, TN, TX, VA, WV

West: AK, AZ, CA, CO, HI, ID, MT, NV, NM, OR, UT, WA, WY.

#### **Bibliography**

CDC. <u>Monitoring selected national HIV prevention and care objectives by using HIV</u> <u>surveillance data—United States and 6 dependent areas, 2016</u>. HIV Surveillance Supplemental Report 2018;23(4). CDC. <u>Estimated HIV incidence and prevalence in the United States</u>, 2010–2016. HIV Surveillance Supplemental Report 2019;24(No. 1)

CDC. <u>Diagnoses of HIV infection in the United States and dependent areas, 2017</u>. HIV Surveillance Report 2018;29.

CDC. Deaths: Final Data for 2014. National Vital Statistics Reports 2016;65(4).

**Content Source:** <u>Centers for Disease Control and Prevention</u> **Date last updated:** March 13, 2019

https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics

# 2. Impact on Racial and Ethnic Minorities

### What Is the Impact of HIV on Racial and Ethnic Minorities in the U.S.?

In the United States, HIV is spread mainly through anal or vaginal sex or by sharing drug-use equipment with an infected person. Although these risk factors are the same for everyone, some racial/ethnic groups are more affected than others, given their percentage of the population. This is because some population groups have higher rates of HIV in their communities, thus raising the risk of new infections with each sexual or drug use encounter.

Additionally, a range of social, economic, and demographic factors—such as stigma, discrimination, income, education, and geographic region—affect their risk for HIV. To learn about the HIV prevention challenges for various racial and ethnic minorities in the United States, see the following CDC fact sheets:

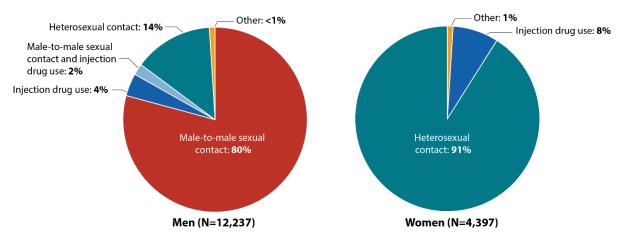
# HIV and African Americans

Blacks/African Americans<sup>a</sup> account for a higher proportion of new HIV diagnoses<sup>b</sup> and people living with HIV, compared to other races/ethnicities. In 2017, blacks/African Americans accounted for 13% of the US population<sup>c</sup> but 43% (16,694) of the 38,739 new HIV diagnoses in the United States and dependent areas.<sup>d</sup>

The Numbers

### **HIV Diagnoses**

# New HIV Diagnoses Among Blacks/African Americans by Transmission Category and Sex in the US and Dependent Areas, 2017

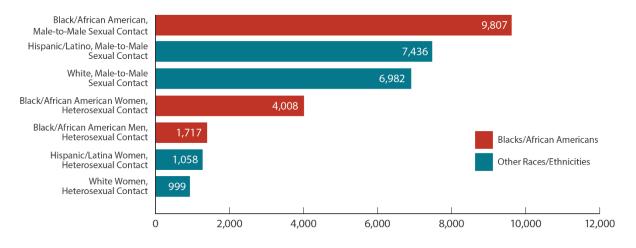


Source: CDC. <u>Diagnoses of HIV infection in the United States and dependent areas, 2017</u>. *HIV Surveillance Report* 2018;29.

In 2017:

- Seventy-three percent (12,237) of adult and adolescent blacks/African Americans who received an HIV diagnosis were men and 26% (4,397) were women.
- Sixty percent (10,070) of blacks/African Americans who received an HIV diagnosis were gay or bisexual men.<sup>e,f</sup>
- Among black/African American gay and bisexual men who received an HIV diagnosis, 41% (4,088) were aged 25 to 34.

# New HIV Diagnoses in the US and Dependent Areas for the Most-Affected Subpopulations, 2017



Hispanics/Latinos can be of any race.

Subpopulations representing 2% or less of HIV diagnoses are not reflected in this chart.

Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. HIV Surveillance

Report 2018;29.

From 2010 to 2016, HIV diagnoses decreased 12% among blacks/African Americans overall in the 50 states and the District of Columbia. But trends varied for different groups of blacks/African Americans.

# HIV Diagnoses Among Blacks/African Americans in the 50 States and District of Columbia, 2010-2016



CDC. NCHHSTP AtlasPlus. Accessed January 24, 2019.

# Living With HIV

In the 50 states and the District of Columbia:

An estimated 468,800 blacks/African Americans had HIV in 2015, representing 42% of all people with HIV.<sup>9</sup> Of those, an estimated 85% were aware of their infection.

# For Every 100 Blacks/African Americans With HIV In 2015:



transmitting HIV to HIV-negative partners.

### Deaths

In 2016, there were 6,804 deaths among blacks/African Americans with diagnosed HIV in the US. These deaths may be due to any cause.

# **Prevention Challenges**

**1 in 7 blacks/African Americans with HIV are unaware they have it**. People who do not know they have HIV cannot take advantage of HIV care and treatment and may unknowingly pass HIV to others.

Some African American communities have **higher rates of some sexually transmitted diseases (STDs)** than other racial/ethnic communities. Having another STD can increase a person's chance of getting or transmitting HIV.

**Stigma, fear, discrimination, and homophobia** may place many African Americans at higher risk for HIV.

The poverty rate is higher among African Americans than other racial/ethnic groups. The **socioeconomic issues** associated with poverty—including limited access to high-quality health care, housing, and HIV prevention education—directly and indirectly increase the risk for HIV infection and affect the health of people living with and at risk for HIV. These factors may explain why African Americans have worse outcomes on the **HIV continuum of care**, including lower rates of linkage to care and viral suppression.

#### What CDC Is Doing

**CDC funds state and local health departments and community-based organizations** (CBOs) to deliver effective HIV prevention services for African Americans. For example:

- Under the <u>new integrated HIV surveillance and prevention cooperative agreement</u>, CDC is awarding around \$400 million per year to health departments for surveillance and prevention efforts. This award will direct resources to the populations and geographic areas of greatest need, while supporting core HIV surveillance and prevention efforts across the United States.
- In 2019, CDC will award a new cooperative agreement to strengthen the capacity and improve the performance of the nation's <u>HIV prevention workforce</u>. New elements include dedicated providers for web-based and classroom-based national training and technical assistance tailored within four geographic regions.
- In 2017, CDC <u>awarded</u> nearly \$11 million per year for 5 years to 30 CBOs to provide HIV testing to young gay and bisexual men of color and transgender youth of color, with the goals of identifying undiagnosed HIV infections and linking those who have HIV to care and prevention services.
- In 2015, CDC added three awards to help health departments reduce HIV infections and improve engagement and retention in HIV medical care among gay and bisexual men of color.
  - <u>Targeted Highly-Effective Interventions to Reverse the HIV Epidemic (THRIVE)</u> supports state and local health department demonstration projects to develop community collaborations that provide comprehensive HIV prevention and care services for gay and bisexual men of color at risk for and living with HIV infection.
  - Training and Technical Assistance for THRIVE strengthens the capacity of funded health departments and their collaborative partners to plan, implement, and sustain (through ongoing engagement, assessment, linkage, and retention) comprehensive prevention, care, behavioral health, and social services models for gay and bisexual men of color at risk for and living with HIV infection.
  - <u>Project PrIDE</u> (PrEP, Implementation, Data to Care, and Evaluation) supports 12 health departments in implementing <u>PrEP</u> and <u>Data to Care</u> demonstration projects for gay and bisexual men and transgender persons, with a particular emphasis on persons of color.

- Through its <u>Let's Stop HIV Together</u> campaigns and partnerships, CDC provides African Americans with effective and culturally appropriate messages about HIV prevention and treatment. For example,
  - <u>Stop HIV Stigma</u> fights stigma among all Americans and provides many stories about people living with HIV.
  - <u>Doing It</u> encourages all adults to know their HIV status and protect themselves and their community by making HIV testing a part of their regular health routine.
  - <u>Start Talking. Stop HIV.</u> helps gay and bisexual men communicate about testing and a range of HIV prevention strategies.
  - <u>HIV Treatment Works</u> shows how people living with HIV have overcome barriers to stay in care and provides resources on how to live well with HIV.
  - <u>Partnering and Communicating Together (PACT) to Act Against AIDS</u>, a 5-year partnership with organizations such as the National Black Justice Coalition, the National Urban League, and the Black Men's Xchange, is raising awareness about testing, prevention, and retention in care among populations disproportionately affected by HIV, including African Americans.

•

<sup>a</sup> *Black* refers to people having origins in any of the black racial groups of Africa, including immigrants from the Caribbean, and South and Latin America. *African American* is a term often used for Americans of African descent with ancestry in North America. Individuals may self-identify as either, both, or choose another identity altogether. This fact sheet uses *African American*, unless referencing surveillance data.

<sup>b</sup> *HIV diagnoses* refers to the number of people who received an HIV diagnosis during a given time period, not when the people got HIV infection.

° The US Census Bureau's population estimates include the 50 states, the District of Columbia, and Puerto Rico.

<sup>d</sup> Unless otherwise noted, the term *United States* (US) includes the 50 states, the District of Columbia, and the 6 dependent areas of American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the US Virgin Islands.

<sup>e</sup> The term *male-to-male sexual contact* is used in CDC surveillance systems. It indicates a behavior that transmits HIV infection, not how individuals self-identify in terms of their sexuality. This fact sheet uses the term *gay and bisexual men*.

<sup>r</sup> Includes infections attributed to male-to-male sexual contact *and* injection drug use (men who reported both risk factors).

<sup>9</sup> Includes diagnosed and undiagnosed HIV infections among adults and adolescents.

Bibliography

- 1. CDC. <u>Changes in the disparity of HIV diagnosis rates among Black women—United States, 2010–</u> 2014. *MMWR* 2017;66(4);104-6.
- 2. CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. *HIV Surveillance Report* 2018;29.
- 3. CDC. Estimated incidence and prevalence in the United States, 2010-2015. *HIV Surveillance Supplemental Report* 2018;23(1).
- CDC. High-impact HIV prevention: CDC's approach to reducing HIV infections in the United States.
- CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2015. *HIV Surveillance Supplemental Report* 2017;22(2).
- 6. CDC. NCHHSTP AtlasPlus. Accessed January 24, 2019.
- 7. US Census Bureau. Income and poverty in the United States: 2017. Accessed January 22, 2019.
- US Census Bureau. <u>Health insurance coverage in the United States: 2017</u>. Accessed January 22, 2019.

https://www.cdc.gov/hiv/group/racialethnic/africanamericans/index.html

#### HIV and African American Gay and Bisexual Men

Black/African American<sup>a</sup> gay, bisexual, and other men who have sex with men<sup>b</sup> are more affected by HIV than any other group in the United States. In 2017, black/African American gay and bisexual men accounted for 26% (10,070) of the 38,739 new HIV diagnoses and 37% of new diagnoses among all gay and bisexual men in the United States and dependent areas.<sup>cd</sup>

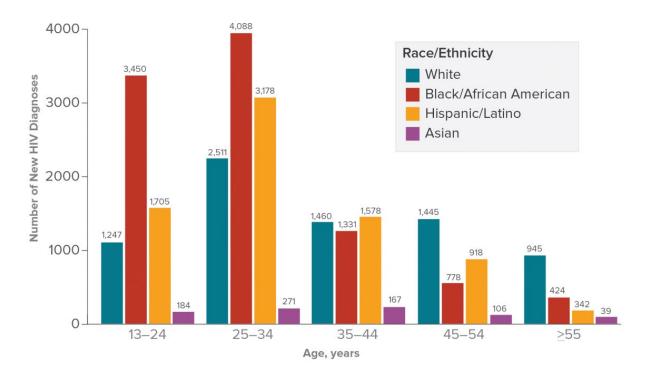
# The Numbers

### **HIV Diagnoses**<sup>®</sup>

#### OF THE 38,739 NEW HIV DIAGNOSES IN THE US AND DEPENDENT AREAS IN 2017, 10,070 WERE AMONG ADULT AND ADOLESCENT BLACK/AFRICAN AMERICAN GAY AND BISEXUAL MEN.

BLACK/AFRICAN AMERICAN GAY AND BISEXUAL MEN MADE UP 37% OF HIV DIAGNOSES AMONG ALL GAY AND BISEXUAL MEN 3 OUT OF 4 BLACK/AFRICAN AMERICAN GAY AND BISEXUAL MEN WHO RECEIVED AN HIV DIAGNOSIS WERE AGED 13 TO 34

### New HIV Diagnoses Among Gay and Bisexual Men in the US and Dependent Areas By Age and Race/Ethnicity, 2017

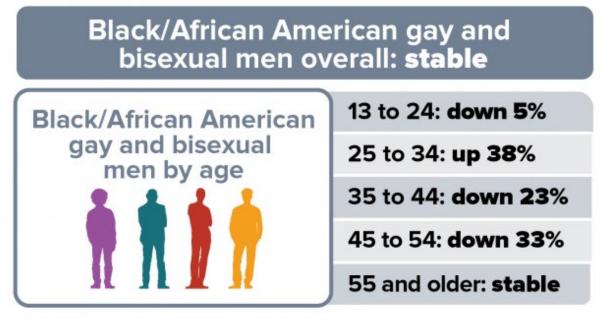


Hispanics/Latinos can be of any race.

Subpopulations representing 2% or less of HIV diagnoses among gay and bisexual men are not reflected in this chart.

Source: CDC. <u>Diagnoses of HIV infection in the United States and dependent areas</u>, <u>2017</u>. *HIV Surveillance Repor*t 2018;29. From 2010 to 2016, HIV diagnoses remained stable overall among black/African American gay and bisexual men in the 50 states and the District of Columbia. But trends for HIV diagnoses among black/African American gay and bisexual men varied by age.<sup>d</sup>

# HIV Diagnoses Among Black/African American Gay and Bisexual Men in the US and Dependent Areas, 2010-2016



CDC. NCHHSTP AtlasPlus. Accessed July 24, 2019.

# Living With HIV

#### Adult and Adolescent Black/African American Gay and Bisexual Men With HIV in the 50 States and the District of Columbia



\* Includes infections attributed male-to-male sexual contact only. Among black/African American men with HIV infection attributed to male-to-male sexual contact and injection drug use, 94% knew they had HIV.
\* Had 2 viral load or CD4 tests at least 3 months apart in a year.
\* Based on most recent viral load test.

#### Source: CDC. Estimated HIV incidence and prevalence in the United States 2010–2016. HIV Surveillance Supplemental Report 2019;24(1).

Source: CDC. <u>Selected national HIV prevention and care outcomes</u> (slides). Accessed September 25, 2019.

#### Deaths

In 2016, there were 2,406 deaths among black/African American gay and bisexual men with diagnosed HIV in the US. These deaths may be due to any cause.<sup>d</sup>

### **Prevention Challenges**

Stigma, homophobia, and discrimination put gay and bisexual men of all races/ethnicities at risk for multiple physical and mental health problems and affects whether they seek and are able to receive high-quality health services, including HIV testing, treatment, and other prevention services. In addition to stigma and other risk factors affecting <u>all gay and bisexual men</u>, several factors are particularly important for African American gay and bisexual men. These include the following:



**Lack of awareness of HIV status.** People who don't know they have HIV cannot get the medicine they need to stay healthy and prevent transmitting HIV to their partners. Therefore, they may transmit the infection to others without knowing it.



**Timely linkage to HIV medical care.** According to a <u>recent *MMWR*</u>, only 67% of HIV-positive African American gay and bisexual men with newly diagnosed HIV, and 58% with previously diagnosed HIV, were linked to HIV medical care within 90 days of the diagnosis. Early linkage to HIV medical care is essential to achieving viral suppression.



Low percentages of viral suppression. African American gay and bisexual men have lower percentages of viral suppression compared to gay and bisexual men of other races/ethnicities. Because of the low percentages of viral suppression, the higher prevalence of HIV in that population, and the greater likelihood of having sexual partners of the same race, compared with other

races/ethnicities, African American gay and bisexual men are at greater risk of being exposed to HIV.



**Socioeconomic factors.** The poverty rate is higher among African Americans than other racial/ethnic groups. The socioeconomic issues associated with poverty—including limited access to high-quality health care, housing, and HIV prevention education—directly and indirectly increase the risk of HIV infection for some African American gay and bisexual men and may also affect the health of people who have HIV.

#### What CDC Is Doing

CDC and its partners are pursuing a <u>high-impact prevention</u> approach to maximize the effectiveness of current HIV prevention interventions and strategies among African American gay and bisexual men. Funding state, territorial, and local health departments is CDC's largest investment in HIV prevention.

- Under the <u>strategic partnerships and planning cooperative agreement</u>, CDC will fund a national organization to support integrated HIV programs through the development of strategic national partnerships and enhanced communication efforts. This funding opportunity will also provide funding to health departments to engage community partners in a planning process to help develop jurisdictional <u>Ending the HIV Epidemic</u> plans.
- In 2017, CDC <u>awarded</u> nearly \$11 million per year for 5 years to 30 CBOs to provide HIV testing to young gay and bisexual men of color and transgender youth of color, with the goals of identifying undiagnosed HIV infections and linking those who have HIV to care and prevention services.
- Under the <u>integrated HIV surveillance and prevention cooperative agreement</u>, CDC awarded around \$400 million per year to health departments for HIV data collection and prevention efforts. This award directs resources to the populations and geographic areas of greatest need, while supporting core HIV surveillance and prevention efforts across the US.
- In 2019, CDC awarded a <u>cooperative agreement</u> to strengthen the capacity and improve the performance of the nation's HIV prevention workforce. New elements include dedicated providers for web-based and classroom-based national training, and technical assistance tailored within four geographic regions.

- Under the <u>flagship community-based organization cooperative agreement</u>, CDC awarded about \$42 million per year to community organizations. This award directs resources to support the delivery of effective HIV prevention strategies to people at greatest risk.
- Through its <u>Let's Stop HIV Together</u> (formerly Act Against AIDS) campaign, CDC provides African American gay and bisexual men with effective and culturally appropriate messages about HIV testing, prevention, and treatment. For example,
  - <u>Stop HIV Stigma</u> highlights the role that each person plays in stopping HIV stigma and gives voice to people living with HIV, as well as their friends and family.
  - o <u>Doing It</u> motivates all adults to get tested for HIV and know their status.
  - <u>Start Talking. Stop HIV</u>. focuses on gay and bisexual men and encourages open communication between sex partners and friends about HIV prevention strategies.
  - <u>HIV Treatment Works</u> shows how people with HIV have been successful getting care and staying on treatment.
  - <u>Partnering and Communicating Together (PACT)</u> raises awareness about testing, prevention, and retention in care among populations disproportionately affected by HIV, including African American gay and bisexual men.

To learn more about a range of health issues affecting African American gay and bisexual men, visit the <u>CDC Gay and Bisexual Men's Health site</u>.

Black refers to people having origins in any of the black racial groups of Africa, including immigrants from the Caribbean, and South and Latin America. African American is a term often used for Americans of African descent with ancestry in North America. Individuals may self-identify as either, both, or choose another identity altogether. This fact sheet uses African American, unless referencing surveillance data.

<sup>b</sup> The term *male-to-male sexual contact* is used in CDC surveillance systems. It indicates a behavior that transmits HIV infection, not how individuals self-identify in terms of their sexuality. This fact sheet uses the term *gay and bisexual men*.

<sup>c</sup> Unless otherwise noted, the term *United States* includes the 50 states, the District of Columbia, and the 6 dependent areas of American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the US Virgin Islands.

<sup>a</sup> Includes infections attributed to male-to-male sexual contact *and* injection drug use (men who reported both risk factors).

• *HIV diagnoses* refers to the number of people who received an HIV diagnosis during a given time period, not when the people got HIV infection.

Bibliography

- 1. CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. *HIV Surveillance Report* 2018;29.
- 2. CDC. Estimated incidence and prevalence in the United States 2010-2016. *HIV Surveillance Supplemental Report* 2018;23(1).
- CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2017. HIV Surveillance Supplemental Report 2019;24(3).
- CDC. HIV infection risk, prevention, and testing behaviors among men who have sex with men— National HIV Behavioral Surveillance, 20 U.S. cities, 2014. *HIV Surveillance Special Report* 2016;15.
- 5. CDC. HIV surveillance—Men who have sex with men (slides). Accessed July 24, 2019.
- CDC. High-impact HIV prevention: CDC's approach to reducing HIV infections in the United States. Accessed July 24, 2019.
- 7. CDC. <u>HIV care outcomes among men who have sex with men with diagnosed HIV infection</u>— <u>United States, 2015</u>. *MMWR* 2017;66(37):969-74.
- Marano M, Stein R, Song W, et al. <u>HIV testing, linkage to HIV medical care, and interviews for</u> partners services among black men who have sex with men—non-health care facilities, 20 <u>southern U.S. jurisdictions, 2016</u>. *MMWR* 2018;67(28):778-81.

https://www.cdc.gov/hiv/group/msm/bmsm.html

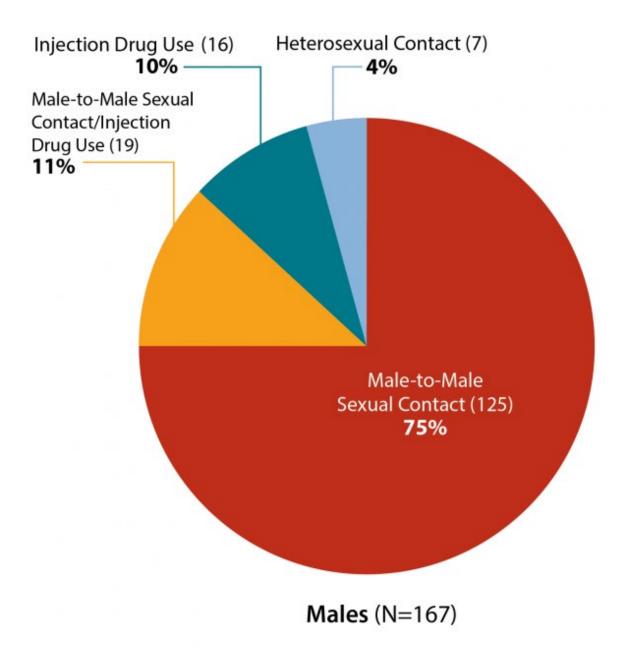
#### **HIV and American Indians and Alaska Natives**

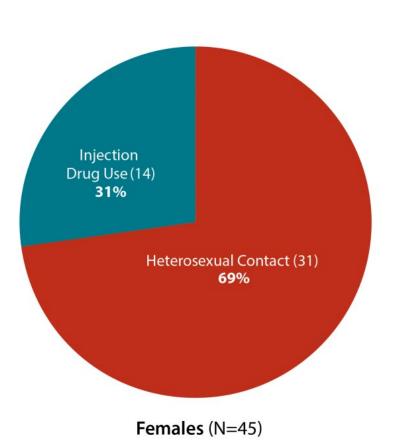
American Indians and Alaska Natives (AI/AN) represent about 1.3%<sup>a</sup> of the U.S. population. Overall, diagnosed HIV infections among AI/AN are proportional to their population size, but HIV diagnoses have increased over time.

#### The Numbers

HIV and AIDS Diagnoses<sup>b</sup>

# HIV Diagnoses Among American Indians/Alaska Natives in the US and Dependent Areas by Transmission Category and Sex, 2017<sup>c</sup>





The terms *male-to-male sexual contact* and *male-to-male sexual contact and injection drug use* are used in the CDC surveillance systems. They indicate the behaviors that transmit HIV infection, not how individuals self-identify in terms of their sexuality.

Source: CDC. <u>Diagnoses of HIV infection in the United States and dependent areas, 2017</u>. HIV Surveillance Report 2018;29.

- Of the 38,739 HIV diagnoses in the United States in 2017, 1% (212) were among AI/AN.
- From 2010 to 2016, the annual number of HIV diagnoses increased 46% (from 157 to 230) among AI/AN overall and 81% (from 90 to 163) among AI/AN gay and bisexual men.<sup>d</sup>

### Living With HIV and Deaths

In the 50 states and the District of Columbia:

- An estimated 3,600 AI/AN had HIV in 2016 and 82% of them had received a diagnosis.
- Of AI/AN with HIV in 2015, 60% received HIV care, 43% were retained in care, and 48% had achieved viral suppression.<sup>e</sup>



People with HIV who take HIV medicine as prescribed and get and keep an undetectable viral load (or stay virally suppressed) have effectively no risk of transmitting HIV to their HIV-negative sexual partners.

• During 2016, 46 AI/AN with diagnosed HIV died in the US. These deaths may be due to any cause.

#### **Prevention Challenges**

- Sexually transmitted diseases (STDs). From 2013 to 2017, AI/AN had the second highest rates of chlamydia and gonorrhea among all racial/ethnic groups. Having another STD increases a person's risk for getting or transmitting HIV.
- Awareness of HIV status. An estimated 8 in 10 AI/AN with HIV in 2016 had received a diagnosis. It is important for everyone to know their HIV status. People who do not know they have HIV cannot take advantage of HIV care and treatment and may unknowingly pass HIV to others.
- **Cultural stigma and confidentiality concerns.** Al/AN gay and bisexual men may face culturally based stigma and confidentiality concerns that could limit opportunities for education and HIV testing, especially among those who live in rural communities or on reservations.
- **Cultural diversity.** There are over 560 federally recognized AI/AN tribes, whose members speak over 170 languages. Because each tribe has its own culture, beliefs, and practices, creating culturally appropriate prevention programs for each group can be challenging.
- **Socioeconomic issues.** Poverty, including limited access to high-quality housing, directly and indirectly increases the risk for HIV infection and affects the health of people who have and are at risk for HIV infection. Compared with other racial/ethnic groups, AI/AN have higher poverty

rates, have completed fewer years of education, are younger, are less likely to be employed, and have lower rates of health insurance coverage.

- Alcohol and illicit drug use. Alcohol and substance use can impair judgment and lead to behaviors that increase the risk of HIV. Injection drug use can directly increase the risk of HIV through sharing contaminated needles, syringes, and other equipment. Compared with other racial/ethnic groups, AI/AN tend to use alcohol and drugs at a younger age and use them more often and in higher quantities.
- **Data limitations.** Racial misidentification of AI/AN may lead to the undercounting of this population in HIV surveillance systems and may contribute to the underfunding of targeted services for AI/AN.

### What CDC Is Doing

CDC and its partners are pursuing a **high-impact prevention** approach to maximize the effectiveness of current HIV prevention methods and **improve HIV data collection among AI/AN**. Activities include:

- Under the <u>new integrated HIV surveillance and prevention cooperative agreement</u>, CDC is awarding around \$400 million per year to health departments for surveillance and prevention efforts. This award will direct resources to the populations and geographic areas of greatest need, while supporting core HIV surveillance and prevention efforts across the United States.
- In 2019, CDC will award a new cooperative agreement to strengthen the capacity and improve the performance of the nation's <u>HIV prevention workforce</u>. New elements include dedicated providers for web-based and classroom-based national training and technical assistance tailored within four geographic regions.
  - Ensuring that capacity-building assistance providers incorporate cultural competency, linguistics, and educational appropriateness into all services delivered.
- Through its <u>Let's Stop HIV Together</u> (formerly Act Against AIDS) campaigns and partnerships, CDC provides effective and culturally appropriate messages aimed at stopping HIV stigma and promoting HIV testing, prevention, and treatment. The <u>stigma</u> materials include <u>stories</u> and issues relevant to AI/AN, as do the following:
  - <u>Doing It</u> encourages all people to know their HIV status and protect themselves and their community by making HIV testing a part of their regular health routine.
  - <u>Start Talking. Stop HIV.</u> helps gay and bisexual men communicate about testing and a range of HIV prevention strategies.

- <u>HIV Treatment Works</u> shows how people living with HIV have overcome barriers to stay in care and provides resources on how to live well with HIV.
- <u>Partnering and Communicating Together (PACT) to Act Against AIDS</u>, a 5-year partnership with organizations such as the ASPIRA Association and AIDS United, is raising awareness about testing, prevention, and retention in care among populations disproportionately affected by HIV, including AI/AN.

In addition, the Office for State, Tribal, Local, and Territorial Support (OSTLTS) serves as the primary link between CDC, the Agency for Toxic Substance and Disease Registry, and tribal governments. OSTLTS's tribal support activities are focused on fulfilling CDC's supportive role in ensuring that AI/AN communities receive public health services that keep them safe and healthy.

<sup>a</sup> Percentage of Al/AN reporting only one race. The US Census Bureau's population estimates include the 50 states, the District of Columbia, and Puerto Rico.

<sup>b</sup> *HIV diagnoses* refers to the number of people who received an HIV diagnosis during a given time period, not when the people got HIV infection.

Unless otherwise noted, the term United States includes the 50 states, the District of Columbia, and the 6
 dependent areas of American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the US Virgin Islands.

<sup>d</sup>Includes infections attributed to male-to-male sexual contact *and* injection drug use (men who reported both risk factors).

People are considered retained in care if they get two viral load or CD4 tests at least 3 months apart in a year. (CD4 cells are the cells in the body's immune system that are destroyed by HIV.) Viral suppression is based on the most recent viral load test.

Bibliography

- 1. CDC. Estimated HIV incidence and prevalence in the United States, 2010–2016. *HIV Surveillance Supplemental Report*2019;24(1).
- US Census Bureau. <u>QuickFacts United States</u>: American Indians and Alaska Natives. Accessed February 5, 2019.
- CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. HIV Surveillance Report 2018;29. Accessed February 5, 2019.
- 4. CDC. NCHHSTP AtlasPlus. Accessed February 21, 2019.
- CDC. High-impact HIV prevention: CDC's approach to reducing HIV infections in the United States. Accessed February 5, 2019.

- CDC. Improving HIV surveillance among American Indians and Alaska Natives in the United States(https://www.cdc.gov/hiv/pdf/policies\_strategy\_nhas\_native\_americans.pdf). Accessed February 5, 2019.
- CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas—2015. *HIV Surveillance Supplemental Report* 2017;22(2). Accessed February 5, 2019.
- 8. CDC. <u>Selected national HIV prevention and care outcomes</u> (slides). Accessed February 5, 2019.
- 9. CDC. Sexually transmitted disease surveillance 2017 (slides). Accessed February 5, 2019.
- Burks DJ, Robbins R, Durtschi JP. American Indian gay, bisexual and two-spirit men: A rapid assessment of HIV/AIDS risk factors, barriers to prevention and culturally-sensitive intervention. *Cult Health Sex* 2011;13(3):283-98. <u>PubMed Abstract</u>.
- 11. Bureau of Indian Affairs. Indian entities recognized and eligible to receive services from the United States Bureau of Indian Affairs. *Fed Regist* 2012;77(155):47868. Accessed February 5, 2019.
- 12. James C, Schwartz K, Berndt J. A profile of American Indians and Alaska Natives and their health coverage. Menlo Park, CA: Henry J. Kaiser Family Foundation; 2009. Accessed February 5, 2019.
- Walters KL, Simoni JM, Evans-Campbell T. Substance use among American Indians and Alaska Natives: Incorporating culture in an 'Indigenist' stress-coping paradigm. *Public Health Rep* 2002;117(1):s104-17. <u>PubMed Abstract</u>.
- Bertolli J, Lee LM, Sullivan PS, American Indian/Alaska Native Race/Ethnicity Data Validation Workgroup. Racial misidentification of American Indians/Alaska Natives in the HIV/AIDS reporting systems of five states and one urban health jurisdiction, US, 1984–2000. *Public Health Rep* 2007;122(3):382-94. <u>PubMed Abstract</u>.
- CDC. Deaths: Final data for 2015. National Vital Statistics Reports 2017; 66(6). Accessed January 26, 2018.

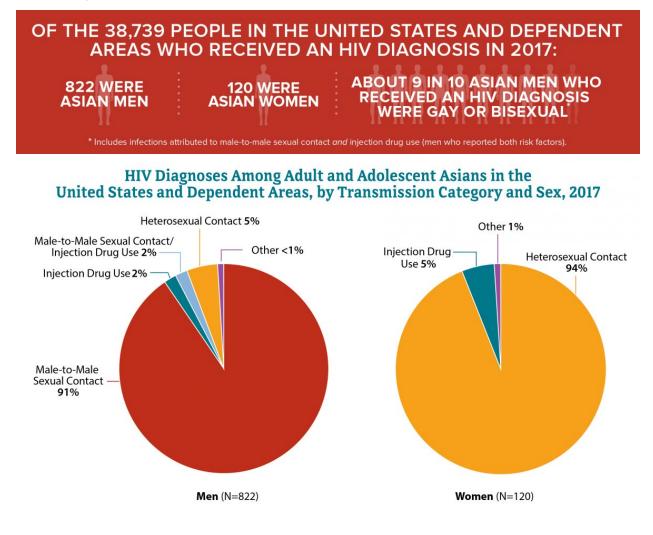
#### https://www.cdc.gov/hiv/group/racialethnic/aian/index.html

#### **HIV and Asians**

Between 2010 and 2016 the Asian population<sup>a</sup> in the United States grew around 17%, four times as fast as the total US population.<sup>b</sup> During the same period, in the 50 states and the District of Columbia, the number of Asians receiving an HIV diagnosis increased by 42%, driven primarily by an increase in HIV diagnoses among Asian gay and bisexual men.<sup>c</sup> Asians, who make up 6% of the population, accounted for about 2% of HIV diagnoses in 2017 in the United States and dependent areas.<sup>d</sup>

The Numbers

#### **HIV Diagnoses**<sup>e</sup>



Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. HIV Surveillance

Report 2018;29.



From 2010 to 2016, annual HIV diagnoses in the 50 states and the District of Columbia increased by 52% among Asian gay and bisexual men.<sup>f</sup>

Living With HIV and Deaths

### Asians With HIV in the 50 States and the District of Columbia



During 2016, there were 95 deaths among Asians with diagnosed HIV in the US and dependent areas. These deaths may be due to any cause.

#### **Prevention Challenges**

There are some behaviors that put everyone at risk for HIV. These include having anal or vaginal sex without protection (like a condom or medicine to prevent or treat HIV) or sharing injection drug equipment with someone who has HIV. Other factors that affect Asians particularly include:

- Undiagnosed HIV. People with undiagnosed HIV cannot obtain the care they need to stay healthy and may unknowingly transmit HIV to others. A lower percentage of Asians with HIV have received a diagnosis, compared to other races/ethnicities.
- **Cultural factors**. Some Asians may avoid seeking testing, counseling, or treatment because of language barriers or fear of discrimination, the stigma of homosexuality, immigration issues, or fear of bringing shame to their families.
- **Limited research**. Limited research about Asian health and HIV infection means there are few targeted prevention programs and behavioral interventions for this population.
- **Data limitations**. The reported number of HIV cases among Asians may not reflect the true HIV diagnoses in this population because of race/ethnicity misidentification. This could lead to the underestimation of HIV infection in this population.

#### What CDC Is Doing

CDC and its partners are pursuing a <u>high-impact prevention</u> approach to maximize the effectiveness of current HIV prevention interventions and strategies and improve surveillance among Asians.

Funding state, territorial, and local health departments is CDC's largest investment in HIV prevention.

- Under the <u>new integrated HIV surveillance and prevention cooperative agreement</u>, CDC awarded around \$400 million per year to health departments for surveillance and prevention efforts. This award directs resources to the populations and geographic areas of greatest need, while supporting core HIV surveillance and prevention efforts across the United States.
- In 2019, CDC awarded a <u>new cooperative agreement</u> to strengthen the capacity and improve the performance of the nation's HIV prevention workforce. New elements include dedicated providers for web-based and classroom-based national training, and technical assistance tailored within four geographic regions. The <u>Asian and Pacific Islander American Health</u> <u>Forum</u> is funded under this effort.
- Under the <u>flagship community-based organization cooperative agreement</u>, CDC awarded about \$42 million per year to community organizations. This award directs resources to support the delivery of effective HIV prevention strategies to people at greatest risk. <u>Special Service for</u> <u>Groups/APAIT</u> is funded under this effort.
- The CDC publication, <u>Effective HIV Surveillance Among Asian Americans and Native Hawaiians</u> <u>and Other Pacific Islanders</u>, provides recommendations for improving HIV surveillance activities for health departments in states with high concentrations of Asians and NHOPIs. CDC continues to collect and report data for Asian and NHOPI populations separately in annual, supplemental, and special <u>surveillance reports</u> and annual <u>program monitoring reports</u>.
- Through its <u>Let's Stop HIV Together</u> (formerly Act Against AIDS) campaigns and partnerships, CDC provides Asians with effective and culturally appropriate messages aimed at stopping HIV stigma and promoting HIV testing, prevention, and treatment. The <u>stigma</u> materials include <u>stories</u> and issues relevant to Asians, as do the following:
  - <u>Doing It</u> encourages all people to know their HIV status and protect themselves and their community by making HIV testing a part of their regular health routine.
  - <u>Start Talking. Stop HIV.</u> helps gay and bisexual men communicate about testing and a range of HIV prevention strategies.
  - <u>HIV Treatment Works</u> shows how people living with HIV have overcome barriers to stay in care and provides resources on how to live well with HIV.
  - <u>Partnering and Communicating Together (PACT) to Act Against AIDS</u> is raising awareness about testing, prevention, and retention in care among populations disproportionately affected by HIV, including Asians.

<sup>a</sup> A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

<sup>b</sup> The US Census Bureau's population estimates include the 50 states, the District of Columbia, and Puerto Rico.

Male-to-male sexual contact is the term used in CDC surveillance systems. It indicates a behavior that transmits
 HIV infection, not how individuals self-identify in terms of their sexuality. This fact sheet uses the term gay and
 bisexual men.

<sup>d</sup> American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the US Virgin Islands.

• *Diagnoses* includes the number of people receiving an HIV diagnosis each year (regardless of the year they were infected).

<sup>r</sup> Includes infections attributed to male-to-male sexual contact *and* injection drug use (men who reported both risk factors).

#### Bibliography

- 1. CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. *HIV Surveillance Report 2018*;29. Accessed March 8, 2019.
- CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas—2016. *HIV Surveillance Supplemental Report* 2016;23(4). Accessed March 8, 2019.
- 3. CDC. Estimated HIV incidence and prevalence in the United States 2010–2016. *HIV Surveillance Supplemental Report*. 2018;24. Accessed March 8, 2019.
- 4. CDC. Selected national HIV prevention and care outcomes [slide set]. Accessed March 8, 2019.
- CDC. High-Impact HIV prevention: CDC's approach to reducing HIV infections in the United States. Accessed March 8, 2019.
- 6. CDC. NCHHSTP atlas plus. Accessed March 8, 2019.
- CDC. Effective HIV surveillance among Asian Americans and other Pacific Islanders. Accessed March 8, 2019.
- Hahm HC, Lee J, Rough K, Strathdee SA. <u>Gender power control, sexual experiences, safer sex</u> practices, and potential HIV risk behaviors among Asian-American women. *AIDS Behav* 2012;16(1):179-88.
- Russ LW, Meyer AC, Takahashi LM, et al. <u>Examining barriers to care: provider and client</u> perspectives on the stigmatization of HIV-positive Asian-Americans with or without viral hepatitis <u>co-infection</u>. *AIDS Care* 2012;24(10):1302-7.

10. US Census Bureau. <u>QuickFacts: United States</u>. Accessed March 8, 2019.

https://www.cdc.gov/hiv/group/racialethnic/asians/index.html

#### **HIV and Hispanics/Latinos**

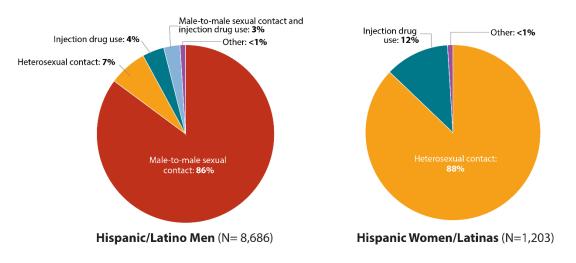
HIV continues to be a serious threat to the health of Hispanic/Latino<sup>a</sup> communities. In 2017, adult and adolescent Hispanics/Latinos made up 26% (9,889) of the 38,739 new HIV diagnoses<sup>b</sup> in the United States (US) and dependent areas.<sup>c</sup>

The Numbers

#### **HIV Diagnoses**

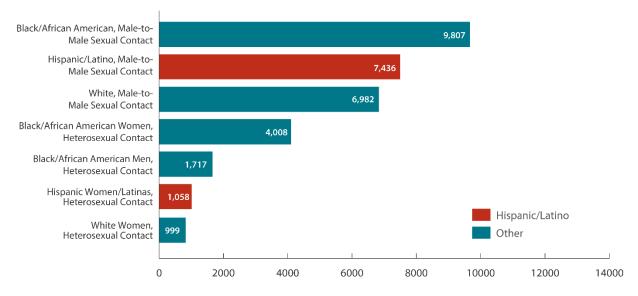


#### New HIV Diagnoses Among Hispanics/Latinos by Transmission Category and Sex in the US and Dependent Areas, 2017



Source: CDC. <u>Diagnoses of HIV infection in the United States and dependent areas, 2017</u>. *HIV Surveillance Report* 2018;29.

#### New HIV Diagnoses Among the Most-Affected Subpopulations in the US and Dependent Areas, 2017



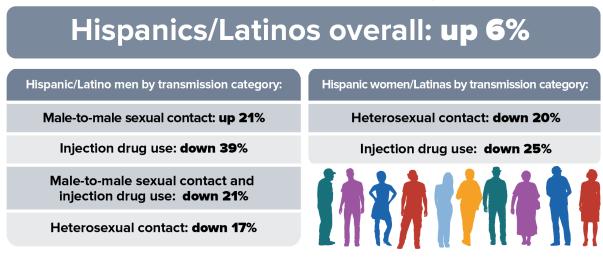
Subpopulations representing 2% or less of HIV diagnoses are not reflected in this chart.

Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. HIV Surveillance

Report 2018;29.

From 2010 to 2016, HIV diagnoses increased 6% among Hispanics/Latinos overall in 50 states and the District of Columbia. But trends varied by transmission category.

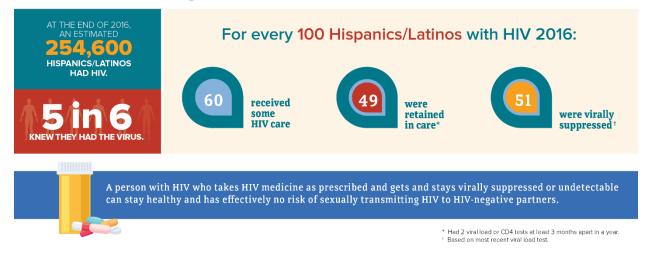
### HIV Diagnoses Among Hispanics/Latinos in 50 States and the District of Columbia, 2010-2016



Source: CDC. NCHHSTP AtlasPlus. Accessed October 8, 2019.

### Living With HIV

#### Adult and Adolescent Hispanics/Latinos With HIV in 50 States and the District of Columbia



Sources: CDC. Estimated HIV incidence and prevalence in the United States 2010–2016. HIV Surveillance Supplemental Report. 2018;24(1).

CDC. NCHHSTP AtlasPlus. Accessed October 8, 2019.

### Deaths

In 2016, there were 2,863 deaths among Hispanics/Latinos with diagnosed HIV in the US and dependent areas. These deaths may be due to any cause.

#### **Prevention Challenges**

- **1 in 6 Hispanics/Latinos with HIV are unaware they have it.** People who do not know they have HIV cannot take advantage of HIV care and treatment and may unknowingly pass HIV to others.
- Hispanics/Latinos have **higher rates of some sexually transmitted diseases (STDs)** than some other races/ethnicities. Having another STD can increase a person's chance of getting or transmitting HIV.
- Poverty, migration patterns, lower educational level, and language barriers may make it harder for some Hispanics/Latinos to get HIV testing and care.
- Some Hispanics/Latinos may not use HIV prevention services, get an HIV test, or get treatment if they have HIV due to **fear of disclosing their immigration status**.

- Hispanics/Latinos experience high levels of **mistrust of the health care system**. Lower levels of trust can reduce the likelihood of clinic visits and result in lower use of and adherence to antiretroviral medications.
- Though not unique to Hispanics/Latinos, **stigma, fear, discrimination, and homophobia** may impact the lives of some Hispanics/Latinos. These issues may put some Hispanics/Latinos at higher risk for HIV infection.

### What CDC Is Doing

CDC and its partners are pursuing a <u>high-impact prevention</u> approach to maximize the effectiveness of current HIV prevention interventions and strategies among Hispanics/Latinos. Funding state, territorial, and local health departments is CDC's largest investment in HIV prevention.

- Under the <u>strategic partnerships and planning cooperative agreement</u>, CDC will fund a national organization to support integrated HIV programs through the development of national partnerships and enhanced communication efforts. This funding opportunity will also provide funding to health departments to engage community partners in a planning process to help develop jurisdictional <u>Ending the HIV Epidemic</u> plans.
- Under the <u>integrated HIV surveillance and prevention cooperative agreement</u>, CDC awarded around \$400 million per year to health departments for HIV data collection and prevention efforts. This award directs resources to the populations and geographic areas of greatest need, while supporting core HIV surveillance and prevention efforts across the US.
- In 2019, CDC awarded a <u>cooperative agreement</u> to strengthen the capacity and improve the performance of the nation's HIV prevention workforce. New elements include dedicated providers for web-based and classroom-based national training, and technical assistance tailored within four geographic regions.
- In 2017, CDC <u>awarded</u> nearly \$11 million per year for 5 years to 30 CBOs to provide HIV testing to young gay and bisexual men of color and transgender youth of color, with the goals of identifying undiagnosed HIV infections and linking those who have HIV to care and prevention services.
- CDC is funding a demonstration project in 4 jurisdictions to identify active HIV transmission networks and implement HIV interventions for Hispanic/Latino gay, bisexual, and other men who have sex with men. Activities include assessing transmission and risk networks, HIV testing, and linking people with HIV to care and treatment.

- Under the <u>flagship community-based organization cooperative agreement</u>, CDC awarded about \$42 million per year to community organizations. This award directs resources to support the delivery of effective HIV prevention strategies to key populations.
- Through its <u>Let's Stop HIV Together</u> campaign (formerly Act Against AIDS), CDC provides Hispanics/Latinos with culturally and linguistically appropriate messages about HIV testing, prevention, and treatment. For example,
  - <u>Stop HIV Stigma</u> highlights the role that each person plays in stopping HIV stigma and gives voice to people living with HIV, as well as their friends and family.
  - o <u>Doing It</u> motivates all adults to get tested for HIV and know their status.
  - <u>Start Talking. Stop HIV</u>. focuses on gay and bisexual men and encourages open communication between sex partners and friends about HIV prevention strategies.
  - <u>HIV Treatment Works</u> shows how people with HIV have been successful getting care and staying on treatment.
  - <u>Partnering and Communicating Together (PACT)</u> raises awareness about testing, prevention, and retention in care among populations disproportionately affected by HIV, including Hispanics/Latinos.

<sup>a</sup> Hispanics/Latinos can be of any race.

<sup>b</sup> *HIV diagnoses* refers to the number of people who received a diagnosis of HIV during a given time period, not when the people got HIV infection.

<sup>c</sup> Unless otherwise noted, the term *United States* (US) includes the 50 states, the District of
 Columbia, and the 6 dependent areas of American Samoa, Guam, the Northern Mariana Islands,
 Puerto Rico, the Republic of Palau, and the US Virgin Islands.

#### Bibliography

- 1. CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. *HIV Surveillance Report* 2018;29.
- 2. CDC. Estimated HIV incidence and prevalence in the United States 2010-2016. *HIV Surveillance Supplemental Report* 2019;24(1).
- CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2017. *HIV Surveillance Supplemental Report* 2019;24(3).
- 4. CDC. <u>NCHHSTP AtlasPlus</u>. Accessed October 8, 2019.
- 5. CDC. Selected national HIV prevention and care outcomes (slides).

- 6. CDC. HIV prevention for Hispanic/Latino gay and bisexual men (issue brief).
- Albarracin J, Plambeck CR. Demographic factors and sexist beliefs as predictors of condom use among Latinos in the USA. *AIDS Care* 2010;22(8):1021-8. <u>PubMed abstract</u>.
- del Rio C. Latinos and HIV care in the Southeastern United States: New challenges complicating longstanding problems. *Clin Infect Dis* 2011;53(5):488-9. <u>PubMed abstract</u>.
- Reisen CA, Zea MC, Bianchi FT, Poppen PJ, Shedlin MG, Penha MM. Latino gay and bisexual men's relationships with non-gay-identified men who have sex with men. J Homosex 2010;57(8):1004-21. PubMed abstract.

https://www.cdc.gov/hiv/group/racialethnic/hispaniclatinos/index.html

#### HIV and Native Hawaiians and Other Pacific Islanders

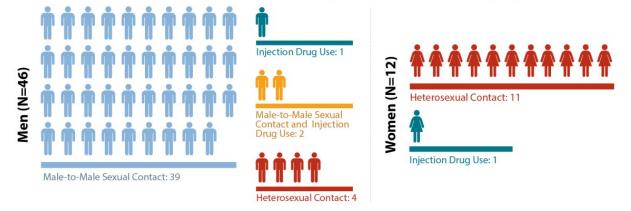
Although Native Hawaiians and Other Pacific Islanders (NHOPI) account for a very small percentage of new HIV diagnoses<sup>a</sup> in the United States (US) and dependent areas,<sup>b</sup> HIV affects NHOPI in ways that are not always apparent because of their small population sizes. In 2017, NHOPI made up 0.2% of the US population.<sup>c</sup>

The Numbers

#### **HIV Diagnoses**



#### New HIV Diagnoses Among Native Hawaiians and Other Pacific Islanders in the US and Dependent Areas by Transmission Category, 2017



Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. HIV Surveillance

Report 2018;29.

From 2010 to 2016, HIV diagnoses decreased 16% among NHOPI overall in the 50 states and the District of Columbia. But trends varied by gender.

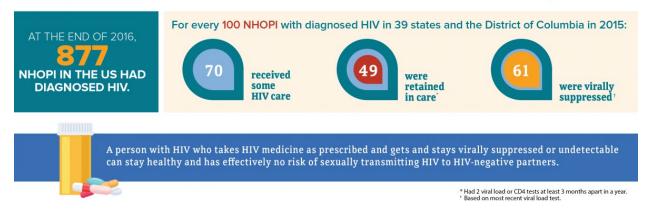
#### HIV Diagnoses Among Native Hawaiians and Other Pacific Islanders in the 50 States and District of Columbia, 2010-2016



Source: CDC. NCHHSTP AtlasPlus. Accessed April 25, 2019.

### **Living With HIV**

#### Adult and Adolescent Native Hawaiians and Other Pacific Islanders With Diagnosed HIV



Source: CDC. <u>Diagnoses of HIV infection in the United States and dependent areas, 2017</u>. *HIV Surveillance Report* 2018;29.

CDC. <u>Selected national HIV prevention and care outcomes</u> (slides). Accessed April 25, 2019.

#### Deaths

In 2016, there were 14 deaths among adult and adolescent NHOPI with diagnosed HIV in the US and dependent areas. These deaths may be due to any cause.

#### **Prevention Challenges**

There are some behaviors that put everyone at risk for HIV. These behaviors include having anal or vaginal sex without protection (like a condom or medicine to prevent or treat HIV), or sharing injection drug equipment with someone who has HIV. Factors that particularly affect NHOPI include:

- Socioeconomic factors. Poverty, inadequate or no health care coverage, language barriers, and lower educational attainment among NHOPI may contribute to lack of awareness about HIV risk and higher-risk behaviors.
- **Cultural factors.** NHOPI cultural customs, such as not talking about sex across generations, may stigmatize sexuality in general, and homosexuality specifically, as well as interfere with HIV risk-reduction strategies, such as condom use.
- Limited research. Limited research about NHOPI health and HIV infection and small population numbers have resulted in a lack of targeted prevention programs and behavioral interventions for this population.

• **Data limitations.** The low reported number of HIV cases among NHOPI may not reflect the true burden of HIV in this population because of race/ethnicity misidentification. This could lead to an underestimation of HIV infection in this population.

#### What CDC Is Doing

CDC and its partners are pursuing a <u>high-impact prevention</u> approach to maximize the effectiveness of current HIV prevention interventions and strategies and improve surveillance among NHOPI. Funding state, territorial, and local health departments is CDC's largest investment in HIV prevention.

- Under the <u>new integrated HIV surveillance and prevention cooperative agreement</u>, CDC awarded around \$400 million per year to health departments for surveillance and prevention efforts. This award directs resources to the populations and geographic areas of greatest need, while supporting core HIV surveillance and prevention efforts across the United States.
- In 2019, CDC awarded a <u>new cooperative agreement</u> to strengthen the capacity and improve the performance of the nation's HIV prevention workforce. New elements include dedicated providers for web-based and classroom-based national training, and technical assistance tailored within four geographic regions. The <u>Asian and Pacific Islander American Health</u> <u>Forum</u> is funded under this effort.
- Under the <u>flagship community-based organization cooperative agreement</u>, CDC awarded about \$42 million per year to community organizations. This award directs resources to support the delivery of effective HIV prevention strategies to people at greatest risk. <u>Special Service for</u> <u>Groups/APAIT</u> is funded under this effort.
- The CDC publication <u>Effective HIV Surveillance Among Asian Americans and Native Hawaiians</u> and Other Pacific Islanders provides recommendations for improving HIV surveillance activities for health departments in states with high concentrations of Asians and NHOPIs. CDC continues to collect and report data for Asian and NHOPI populations separately in annual, supplemental, and special <u>surveillance reports</u> and annual <u>program monitoring reports</u>.
- Through its <u>Let's Stop HIV Together</u> (formerly Act Against AIDS) campaigns and partnerships, CDC provides NHOPI with effective and culturally appropriate messages aimed at stopping HIV stigma and promoting HIV testing, prevention, and treatment. The <u>stigma</u> materials include <u>stories</u> and issues relevant to NHOPI, as do the following:

- <u>Doing It</u> encourages all people to know their HIV status and protect themselves and their community by making HIV testing a part of their regular health routine.
- <u>Start Talking. Stop HIV.</u> helps gay and bisexual men communicate about testing and a range of HIV prevention strategies.
- <u>HIV Treatment Works</u> shows how people living with HIV have overcome barriers to stay in care and provides resources on how to live well with HIV.
- Partnering and Communicating Together (PACT) to Act Against AIDS is raising awareness about testing, prevention, and retention in care among populations disproportionately affected by HIV, including NHOPI.

<sup>a</sup> *HIV diagnoses* refers to the number of people who received an HIV diagnosis during a given time period, not when the people got HIV infection.

<sup>b</sup> Unless otherwise noted, the term *United States* (US) includes the 50 states, the District of Columbia, and the 6 dependent areas of American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the US Virgin Islands.

The US Census Bureau's population estimates include the 50 states, the District of Columbia, and Puerto Rico.
 Bibliography

- 1. CDC. Diagnoses of HIV infection in the United States and dependent areas, 2017. *HIV Surveillance Report* 2018;29.
- 2. CDC. Estimated HIV incidence and prevalence in the United States 2010-2016. *HIV Surveillance Supplemental Report* 2019;24(1).
- CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2016. *HIV Surveillance Supplemental Report* 2018;23(4).
- 4. CDC. <u>NCHHSTP AtlasPlus</u>. Accessed April 25, 2019.
- 5. CDC. Selected national HIV prevention and care outcomes (slides).
- Adih WK, Campsmith M, Williams CL, Hardnett FP, Hughes D. Epidemiology of HIV among Asians and Pacific Islanders in the United States, 2001-2008. *J Int Assoc Physicians AIDS Care* (*Chic*) 2011;10(3):150-9. <u>PubMed abstract</u>.
- DiStefano AS, Hui B, Barrera-Ng A, et al. Contextualization of HIV and HPV risk and prevention among Pacific Islander young adults in Southern California. *Soc Sci Med* 2012;75(4):699-708. <u>PubMed abstract</u>.

 Takahashi LM, Kim AJ, Sablan-Santos L, et al. HIV testing behavior among Pacific Islanders in Southern California: Exploring the importance of race/ethnicity, knowledge, and domestic violence. *AIDS Educ Prev* 2011;23(1):54-64. <u>PubMed abstract</u>.

https://www.cdc.gov/hiv/group/racialethnic/nhopi/index.html

### **Chapter II. Overview**

C. History 1. HIV and AIDS Timeline

### A Timeline of HIV/AIDS

The HIV.gov Timeline reflects the history of the domestic HIV/AIDS epidemic from the first reported cases in 1981 to the present—where advances in HIV prevention, care, and treatment offer hope for a long, healthy life to people who are living with, or at risk for, HIV and AIDS.

### 1981

• June 5: The U.S. Centers for Disease Control and Prevention (CDC) publish a *Morbidity and Mortality Weekly Report* (MMWR), describing cases of a rare lung infection, *Pneumocystis carinii pneumonia* (PCP), in five young, previously healthy, gay men in Los Angeles. All the men have other unusual infections as well, indicating that their immune systems are not working; two have already died by the time the report is published. This edition of the *MMWR* marks the first official reporting of what will become known as the AIDS epidemic.

• June 5-6: The Associated Press, the Los Angeles Times, and the San Francisco Chronicle report on the MMWR article. Within days, CDC receives numerous reports of similar cases of PCP and other opportunistic infections among gay men—including reports of a cluster of cases of a rare, and unusually aggressive, cancer, *Kaposi's Sarcoma* (KS), among a group of gay men in New York and California.

June 8: In response to these reports, CDC establishes the Task Force on Kaposi's Sarcoma and Opportunistic Infections to identify risk factors and to develop a case definition for national surveillance.
July 3: CDC releases another MMWR on KS and PCP among 26 gay men in New York and California. On the same day, the New York Times publishes an article entitled "Rare Cancer Seen in 41 Homosexuals." At this point, the term "gay cancer" enters the public lexicon.

• September 21: The nation's first Kaposi's Sarcoma clinic opens at the University of California, San Francisco Medical Center.

• December 10: Bobbi Campbell, a San Francisco nurse, becomes the first KS patient to go public. Calling himself the "KS Poster Boy," Campbell writes a newspaper column on living with "gay cancer" for the *San Francisco Sentinel*. He also posts photos of his lesions in the window of a local drugstore to alert the community to the disease and encourage people to seek treatment.

• By year's end, there is a cumulative total of 270 reported cases of severe immune deficiency among gay men, and 121 of those individuals have died. Some researchers begin calling the condition *GRID* (Gay-Related Immune Deficiency). This terminology influences both the medical profession and the public to perceive the epidemic as limited to gay men, with serious long-term consequences for women, heterosexual men, hemophiliacs, people who inject drugs, and children.

### 1982

• January 4: Gay Men's Health Crisis, the first community-based AIDS service provider in the

U.S., is founded in New York City.

• April 13: U.S. Representative Henry Waxman convenes the first congressional hearings on AIDS at the Los Angeles Gay and Lesbian Community Services Center in Hollywood, California. At the hearing, Dr. James Curran, head of the CDC's *Task Force on Kaposi's Sarcoma and Opportunistic Infections*, estimates that tens of thousands of people may be affected by the disease.

• May 9: The Kaposi's Sarcoma (KS) Research and Education Foundation is formed to provide information on KS to gay men in San Francisco. The organization will ultimately become the San Francisco AIDS Foundation.

• September 24: CDC uses the term "AIDS" (Acquired Immune Deficiency Syndrome) for the first time, and releases the first case definition of AIDS: "a disease at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known case for diminished resistance to that disease."

• September 24: Rep. Waxman and Rep. Phillip Burton introduce legislation to allocate \$5 million to CDC for surveillance and \$10 million to the National Institutes of Health (NIH) for AIDS research.

• **December 10:** CDC reports a case of AIDS in an infant who received blood transfusions. The following week, the *MMWR* reports 22 cases of unexplained immunodeficiency and opportunistic infections in infants.

### 1983

• January 1: Ward 86, the world's first dedicated outpatient AIDS clinic, opens at San Francisco General Hospital.

• January 4: CDC hosts a public meeting with the representatives from the U.S. Food

and Drug Administration (FDA), NIH, the blood services community, gay activists, and hemophilia specialists to identify opportunities to protect the nation's blood supply from AIDS, but participants fail to reach consensus on appropriate action.

• January 7: CDC reports cases of AIDS in female sexual partners of males with AIDS.

• In February, CDC establishes the National AIDS Hotline to respond to public inquiries about the disease.

• In the March 4 edition of the *Morbidity and Mortality Weekly Report* (MMWR), CDC notes that most cases of AIDS have been reported among homosexual men with multiple sexual partners, people who inject drugs, Haitians, and *hemophiliacs*. The report suggests that AIDS may be caused by an infectious agent that is transmitted sexually or through exposure to blood or blood products and issues recommendations for preventing transmission.

• May 18: The U.S. Congress passes the first bill that includes funding specifically targeted for AIDS research and treatment—\$12 million for agencies within the U.S. Department of Health and Human Services (HHS).

• May 20: Dr. Françoise Barré-Sinoussi and her colleagues at the Pasteur Institute in France report the discovery of a *retrovirus* they call Lymphadenopathy Associated Virus (LAV ) that could be the cause of AIDS.

• In June, people living with AIDS (PLWAs) take over the plenary stage at the National AIDS Forum in Denver, and issue a statement on the right of PLWAs to be at the table when policy is made, to be treated with dignity, and to be called "people with AIDS," not "AIDS victims." The statement becomes known as The Denver Principles [PDF, 19 KB], and it serves as the charter for the founding of the National Association of People with AIDS.

• July 25: San Francisco General Hospital opens Ward 5B, the first dedicated AIDS ward in the U.S. It is fully occupied within days. The ward offers compassionate, holistic care for AIDS patients, and all staff in the ward—from nurses to janitors—have volunteered to work there. This becomes known as the "San Francisco model of care" for HIV-positive patients.

• August 1-2: The U.S. House of Representatives Subcommittee on Government Operations holds hearings on the federal response to AIDS.

• August 8: AIDS activist Bobbi Campbell appears with his partner, Bobby Hilliard, on the cover of *Newsweek* magazine for the story, "Gay America: Sex, Politics, and the Impact of AIDS." It is the first time two gay men are pictured embracing one another on the cover of a U.S. mainstream national magazine.

• September 2: In response to growing concerns about the potential for transmission of AIDS in healthcare settings, CDC publishes the first set of occupational exposure precautions for healthcare workers and allied health professionals.

• In the September 9 *MMWR*, CDC identifies all major routes of HIV transmission—and rules out transmission by casual contact, food, water, air, or environmental surfaces.

• September 30: After a New York doctor is threatened with eviction from his building for treating AIDS patients, the state's Attorney General and Lambda Legal file the first AIDS discrimination lawsuit.

• November 22: The World Health Organization

(WHO) holds its first meeting to assess the global AIDS situation and begins international surveillance.

# 1984

• Community-based AIDS service organizations join together to form *AIDS Action*, a national organization in Washington, DC, to advocate on behalf of people and communities affected by the epidemic, to educate the federal government, and to help shape AIDS-related policy and legislation.

• April 23: HHS Secretary Margaret Heckler announces that Dr. Robert Gallo and his colleagues at the National Cancer Institute have found the cause of AIDS, a *retrovirus* they have labeled HTLV-III. Heckler also announces the development of a diagnostic blood test to identify HTLV-III and expresses hope that a vaccine against AIDS will be produced within two years.

• July 13: CDC states that avoiding injection drug use and reducing needle-sharing "should also be effective in preventing transmission of the virus."

• August 15: AIDS activist Bobbi Campbell dies of AIDS-related illness at age 32.

• In October, San Francisco officials order bathhouses closed due to high-risk sexual activity occurring in these venues. New York follows suit within a year.

# 1985

• January 11: CDC revises the AIDS case definition to note that AIDS is caused by a newly identified virus and issue provisional guidelines for blood

virus and issue provisional guidelines for blood screening.

• March 2: FDA licenses the first commercial blood test, *ELISA*, to detect HIV. Blood banks begin screening the U.S. blood supply.

• April 15–17: HHS and WHO host the first International AIDS Conference in Atlanta, Georgia.

• August 27: Ryan White, an Indiana teenager who contracted AIDS through contaminated blood products used to treat his *hemophilia*, is refused entry to his middle school. His family's protracted legal battles to protect Ryan's right to attend school call national attention to the issue of AIDS, and Ryan chooses to speak out publicly on the need for AIDS education.

• August 31: The Pentagon announces that, beginning October 1, it will begin testing all new military recruits for HIV infection and will reject those who test positive for the virus.

• September 17: President Ronald Reagan mentions AIDS publicly for the first time, calling AIDS "a top priority" and defending his administration against criticisms that funding for AIDS research is inadequate.

• October 2: The U.S. Congress allocates nearly \$190 million for AIDS research—an increase of \$70 million over the Administration's budget request. The House Appropriations Committee also urges President Reagan to appoint an "AIDS czar."

• October 2: Actor Rock Hudson dies of AIDS-related illness at age 59. He is the first major U.S. public figure to acknowledge that he has AIDS, and his death marks a turning point in public perceptions about the epidemic. Hudson leaves \$250,000 to help set up the American Foundation for AIDS Research (amfAR). Actress Elizabeth Taylor serves as the organization's founding National Chairman.

• December 6: The U.S. Public Health Service issues the first recommendations for preventing HIV transmission from mother to child.

• By year's end, at least one HIV case has been reported from each region of the world [PDF, 49 KB].

### 1986

• The Robert Wood Johnson Foundation creates the "AIDS Health Services Program" [PDF, 244 KB], providing joint funding with the U.S. Health Resources and Services Administration (HRSA) for demonstration projects in hard-hit U.S. cities. This program serves as a precursor to the Ryan White CARE Act.

• The International Steering Committee for People with HIV/AIDS is created. Six years later, this will become the GNP+ (Global Network of People Living with HIV/AIDS).

• In May, the International Committee on the Taxonomy of Viruses declares that the virus that causes AIDS will officially be known as *Human Immunodeficiency Virus* (HIV).

• July 18: At the National Conference on AIDS in the Black Community in Washington, DC, a group of minority leaders meets with the U.S. Surgeon General, Dr. C. Everett Koop, to discuss concerns about HIV/AIDS in communities of color. This meeting marks the unofficial founding of the National Minority AIDS Council (NMAC).

• October 22: Dr. Koop issues the Surgeon General's Report on AIDS [PDF, 1.98 MB]. The report makes it clear that HIV cannot be spread casually and calls for: a nationwide education campaign (including early sex education in schools); increased use of condoms; and voluntary HIV testing.

• October 24: CDC reports that AIDS cases are disproportionately affecting African-Americans and Latinos. This is particularly true for African-American and Latino children, who make up 90% of *perinatally* acquired AIDS cases.

• October 29: The Institute of Medicine (IOM), the principal health unit of the National Academy

of Sciences, issues a report, *Confronting AIDS*: Directions for Public Health, Health Care, and

*Research*. The report calls for a "massive media, educational and public health campaign to curb the spread of the HIV infection," as well as for the creation of a National Commission on AIDS. The IOM estimates that the effort will require a \$2 billion investment in research and patient care by the end of the decade.

## 1987

 In February, AIDS activist Cleve Jones creates the nongovernmental organizations; and champion the

first panel of the AIDS Memorial Quilt. rights of those living with HIV.

• February 1: WHO launches The Global Program on • February 4: Emmy-award winning pianist Liberace

AIDS to: raise awareness; formulate evidence-based dies of AIDS-related illness at age 67.

policies; provide technical and financial support to • In March, playwright and AIDS activist Larry Kramer

countries; initiate relevant social, behavioral, and founds ACT UP (the AIDS Coalition to Unleash Power)

biomedical research; promote participation by in New York City.

• March 19: FDA approves the first *antiretroviral* 

drug, zidovudine (AZT). The U.S. Congress

approves \$30 million in emergency funding to

states for AZT—laying the groundwork for what

will be the AIDS Drug Assistance Program (ADAP),

authorized by the Ryan White CARE Act in 1990.

• March 19: FDA issues regulations that expand access to promising new medications that have not yet been approved or licensed by the agency. This accelerates drug approval by 2-3 years.

• March 31: President Ronald Reagan and

French Prime Minister Jacques Chirac end

an international scientific dispute when they

announce that researchers from the two countries

will share credit for discovery of the AIDS virus. The countries agree that patent rights to a blood test that emerged from that discovery will also be shared, with most of the royalties donated to a new foundation for AIDS research and education.

• **April 7:** FDA declares HIV prevention as a new indication for male condoms.

• April 19: Princess Diana makes international headlines when she is photographed shaking the hand of an HIV-positive patient in a London hospital. She goes on to become a passionate advocate for people living with HIV and to speak forcefully against HIV/AIDS-related stigma and discrimination.

• April 29: FDA approves the *Western blot* blood test kit, a more specific test for HIV antibodies.

• May 15: The U.S. Public Health Service adds HIV as a "dangerous contagious disease" to its immigration exclusion list and mandates testing for all visa applicants. The HIV ban will not be lifted until January 4, 2010.

• May 31: President Reagan makes his first public speech about AIDS and establishes a Presidential Commission on HIV.

• August 5: A federal judge orders Florida's DeSoto County School Board to enroll HIV-positive brothers, Ricky, Robert, and Randy Ray. The board had refused to allow the three boys, who are *hemophiliacs*, to attend. After the ruling, outraged town residents refuse to allow their children to attend school, and someone sets fire to the Ray house on August 28, destroying it.

• August 14: CDC issues Perspectives in Disease Prevention and Health Promotion: Public Health Service Guidelines for Counseling and Antibody Testing to Prevent HIV Infection and AIDS.

• August 18: FDA sanctions the first human testing

of a candidate vaccine against HIV.

• September 30: CDC launches the first AIDS-related public service announcements, *America Responds to AIDS*, to kick off the newly designated AIDS Awareness Month in October.

• October 11: The AIDS Memorial Quilt goes on display for the first time on the National Mall in Washington, DC. The display features 1,920 4x8 panels and draws half a million visitors.

• October 14: In a 94-2 vote, the U.S. Senate adopts the Helms Amendment, which requires federally financed educational materials about AIDS to stress sexual abstinence and forbids any material that "promotes" homosexuality or drug use.

• October 22: AIDS becomes the first disease ever debated on the floor of the United Nations (UN) General Assembly. The General Assembly resolves to mobilize the entire UN system in the worldwide struggle against AIDS and designates the WHO to lead the effort.

• In November, journalist Randy Shilts' book about the early years of the HIV/AIDS epidemic, And the Band Played On: Politics, People and the AIDS Epidemic, is published.

• Also in November, Debra Fraser-Howze, director of teenage services at the Urban League of New York, founds the National Black Leadership Commission

on AIDS. The organization works to educate, mobilize, and empower black leaders to meet the challenge of fighting HIV/AIDS and other health disparities in their local communities

• November 13: The American Medical Association declares that doctors have an ethical obligation to care for people with AIDS, as well as for those who have been infected with the virus but show no symptoms.

### 1988

• March 3: Ryan White, an HIV-positive teenager who has become a national spokesperson for AIDS education, testifies before the President's Commission on AIDS.

• In April, the first comprehensive needle-exchange program in North America is established in Tacoma, Washington. San Francisco then establishes what becomes the largest needleexchange program in the nation.

• May 26: The U.S. Surgeon General, C. Everett Koop, launches the U.S.'s first coordinated HIV/AIDS education campaign by mailing 107 million copies of a booklet, *Understanding AIDS* [PDF, 1.1 MB], to all American households. It is the largest public health mailing in history.

• July 23: FDA announces that it will allow the importation of small quantities of unapproved drugs for persons with life-threatening illnesses, including HIV/AIDS.

• October 11: ACT UP protests at FDA headquarters over the slow pace of the federal drug-approval process. Eight days later, FDA announces new regulations to speed up drug approvals.

• October 18: The Abandoned Infants Assistance (AIA) Act [PDF, 674 KB] becomes law; it addresses the issue of so-called "boarder babies." These infants, many of whom have been *perinatally* exposed to drugs or HIV, have been left at hospitals indefinitely by their parents. The AIA funds demonstration projects to support moving these children into safe living arrangements.

• November 4: The Health Omnibus Programs Extension (HOPE) Act authorizes the use of federal funds for AIDS prevention, education, and testing. It is the first comprehensive federal AIDS bill, and it also establishes the National Commission on AIDS and the Office of AIDS Research at NIH.

• November 28: Elizabeth Glaser, an HIV-positive mother of two HIV-positive children, and two of her friends form the Pediatric AIDS Foundation (later renamed the Elizabeth Glaser Pediatric AIDS Foundation) to advocate for research into the care and treatment needs of children living with HIV/AIDS.

• **December 1:** World AIDS Day is observed for the first time. The date is designated by WHO and supported by the UN.

• **December 17:** Sylvester James, Jr., an openly gay, African-American entertainer who uses only his first name, and who is called "the embodiment of disco," dies of AIDS-related illness at age 41.

• **December 20:** Max Robinson, the first African-American network news anchor in the U.S., and a founder of the National Association of Black Journalists, dies of AIDS-related illness at age 49.

• **December 27:** Gay rights activist and writer Joseph Beam dies of an AIDS-related illness at age 33. He is best known for editing *In The Life*, the first collection of writing by gay black men.

• HRSA awards HIV planning grants to 11 states and 10 cities in order to create a plan for HIV/AIDS systems of care, and also funds the first Pediatric AIDS Service Demonstration Grants. These grants lay the groundwork for the statewide programs that will later be funded under the Ryan White CARE Act.

### 1989

• March 9: Photographer Robert Mapplethorpe dies of AIDS-related illness at age 42.

• June 16: Based on recommendations from NIH, the U.S. Public Health Service issues the first guidelines for preventing *Pneumocystis carinii pneumonia*, an AIDS-related *opportunistic*  *infection*, and a major cause of illness and death for people living with AIDS.

• June 23: CDC releases the Guidelines for Prevention of Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Health-Care and Public-Safety Workers.

• In July, Dázon Dixon Diallo founds SisterLove, Inc., the first organization in the U.S. southeastern

states to focus on women living with, or at risk for, contracting HIV.

• August 18: CDC reports that the number of reported AIDS cases in the United States has reached 100,000.

• June 23: Dr. Anthony Fauci, head of NIH's National Institute of Allergy and Infectious Diseases, endorses a "parallel track" approach to clinical trials, which will give a larger number of HIV-positive people access to experimental treatments.

• September 10–17: Members of 50 churches and mosques come together for the first Harlem Week of Prayer for the Healing of AIDS. The event is the brainchild of the Reverend Dr. Pernessa Seele, an African-American immunologist and minister, who goes on to form The Balm in Gilead, a nonprofit organization that works with black faith communities to improve health.

• **September 18:** The National Commission on AIDS meets for the first time.

• **December 1:** African-American choreographer and activist Alvin Ailey dies at age 58 of an AIDS-related illness. In 2014, President Barack Obama chooses Ailey to receive a posthumous Presidential Medal of Freedom—the nation's highest civilian honor.

 HRSA grants \$20 million for HIV care and treatment through the Home-Based and Community-Based Care State grant program. For many states, this is their first involvement in HIV care and treatment.
A CDC/HRSA initiative provides \$11 million to fund seven community health centers to provide HIV counseling and testing services. This is a precursor to what will be part of the Ryan White CARE Act.

### 1990

• January 18: CDC reports the possible transmission of HIV to a patient through a dental procedure performed by an HIV-positive dentist. This episode provokes much public debate about the safety of common dental and medical procedures.

• January 26: The U.S. Public Health Service issues a statement on managing occupational exposure to HIV, including considerations regarding postexposure use of the *antiretroviral* drug, AZT.

• February 16: Pop artist and AIDS activist Keith Haring dies of AIDS-related illness at age 31.

• April 8: Ryan White, the Indiana teen who became an international spokesperson against HIV/AIDS stigma and discrimination, dies of AIDS-related illness at the age of 18.

• May 21: ACT UP protests at the National Institutes of Health. The group demands more HIV treatments and the expansion of clinical trials to include more women and people of color.

June 20–24: The 6th International AIDS Conference meets in San Francisco. To protest U.S. immigration policy that bars people with HIV from entering the country, domestic and international nongovernmental groups boycott the conference.
July 26: The U.S. Congress enacts the Americans with Disabilities Act [PDF, 7.9 MB]. The Act prohibits discrimination against individuals with disabilities,

including people living with HIV/AIDS.

• August 18: The U.S. Congress enacts the Ryan White Comprehensive AIDS Resources Emergency

(CARE) Act of 1990 [PDF, 2.41 MB], which provides \$220.5 million in federal funds for HIV communitybased care and treatment services in its first year. HRSA is given responsibility for managing the program, which is the nation's largest HIV-specific federal grant program.

• October 26: FDA approves use of zidovudine (AZT ) for pediatric AIDS.

• November 28: The U.S. Congress enacts legislation that includes the AIDS Housing Opportunity Act, which creates the Housing Opportunities for People with AIDS (HOPWA) program the following year. Administered by the U.S. Department of Housing and Urban Development (HUD), HOPWA grants provide housing assistance to people living with AIDS.

• **December 17:** In response to the critical, unmet need for HIV prevention and care among Latinos, a group of community leaders forms the Latino Commission on AIDS.

# 1991

• April–May: The Visual AIDS Artists Caucus

launches the *Red Ribbon Project* to create a visual symbol to demonstrate compassion for people living with AIDS and their caregivers. The red ribbon becomes the international symbol of AIDS awareness.

• July 21: CDC recommends restrictions on the practice of HIV-positive healthcare workers. Congress goes on to enact a law requiring states to adopt the CDC restrictions or to develop and adopt their own.

• August 14: The U.S. Congress passes the Terry Beirn Community-Based Clinical Trials Program Act [PDF, 56 KB] to establish a network of community-based clinical trials for HIV treatment. Beirn, an executive and lobbyist at amfAR, played key roles in the passage of the HOPE Act and the Ryan White CARE Act. He died of AIDS-related illness on July 16, 1990, age 39.

• November 7: American basketball star Earvin "Magic" Johnson announces that he is HIV-positive.

• November 24: Freddie Mercury, lead singer/ songwriter of the rock band Queen, dies of AIDSrelated illness at age 45.

• NMAC, in cooperation with the National Association of People With AIDS (NAPWA) and the National AIDS Interfaith Network, holds the first annual National Skills Building Conference, which will later become the United States Conference on AIDS.

## 1992

• In this year, AIDS becomes the number one cause of death for U.S. men ages 25 to 44.

• February 4: The International Olympic Committee rules that athletes with HIV are eligible to compete in the games without restrictions.

• April 8: Arthur Ashe, the former United States Open and Wimbledon tennis champion and an African-American pioneer in sports and social issues, announces that he has AIDS. Ashe, who underwent heart-bypass surgeries in 1979 and 1983, believes he contracted HIV via blood transfusions. He dies of AIDS-related illness on February 3, 1993.

• May 11: The U.S. District Court in Manhattan declares that the Helms Amendment (1987) which requires federally financed educational materials about AIDS to stress sexual abstinence and forbids any material that "promotes" homosexuality or drug use, is unconstitutionally vague.

• May 27: FDA licenses a rapid HIV diagnostic test kit which gives results from a blood test in 10 minutes.

#### • July 19-24:

The 8th International AIDS

Conference is held in Amsterdam. The event was originally scheduled for Boston, but the venue is moved due to U.S. immigration restrictions on people living with HIV/AIDS.

• **December 1:** CDC launches the Business Responds to AIDS program to help large and small businesses meet the challenges of HIV/AIDS in the workplace and the community. (CDC will start the Labor Responds to AIDS program in 1995.)

### 1993

• President Clinton establishes the White House Office of National AIDS Policy (ONAP).

• The National Association of People With AIDS (NAPWA) convenes the first annual "AIDS Watch." Hundreds of community members from across the U.S. come to Washington, DC, to lobby Congress for increased funding.

• January 6: World-renowned ballet dancer Rudolf Nureyev dies of AIDS-related illness at age 54.

• April 13: Angels in America, Tony Kushner's multiact play about AIDS, wins the 1993 Pulitzer Prize for drama.

• May 7: FDA approves the female condom.

• In June, the U.S. Congress enacts the NIH Revitalization Act, giving the Office of AIDS Research primary oversight of all NIH AIDS

research. The Act requires NIH and other research agencies to expand involvement of women and minorities in all research.

• The same act codifies the U.S. HIV immigration exclusion policy into law; President Clinton signs it

on June 10.

• In August, the Women's Interagency HIV Study and HIV Epidemiology Study begin. Both are major U.S. federally funded research studies on women and HIV/ AIDS.

• **December 18:** CDC expands the case definition of AIDS, declaring those with *CD4* counts below 200 to have AIDS.

• In that same report, CDC adds three new conditions pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer—to the list of clinical indicators of AIDS. These new conditions mean that more women and people who inject drugs will be diagnosed with AIDS.

• December 22: The film *Philadelphia*, starring Tom Hanks as a lawyer fired from his job because he has AIDS, opens in theaters. Other earlier films, including the documentary *No Sad Songs* (1985), *Buddies* (1985), *An Early Frost* (1985), and *Longtime Companion* (1989), have addressed AIDS, but *Philadelphia* is the first major Hollywood film on the topic. Hanks will win his first Academy Award for Best Actor for his role.

## 1994

• In this year, AIDS becomes the leading cause of death for all Americans ages 25 to 44.

• February 17: Randy Shilts, a U.S. journalist who covered the AIDS epidemic and who authored And the Band Played On: Politics, People and the AIDS Epidemic, dies of AIDS-related illness at age 42.

• May 20: CDC publishes Guidelines for Preventing Transmission of Human Immunodeficiency Virus Through Transplantation of Human Tissue and Organs.

• August 5: The U.S. Public Health Service recommends that pregnant women be given the antiretroviral drug

AZT to reduce the risk of *perinatal transmission* of HIV.

• November 11: Pedro Zamora, a member of the cast of MTV's popular television show, "The Real World," dies of AIDS-related illness at age 22.

• **December 23:** FDA approves an oral HIV test, the first non-blood-based antibody test for HIV.

• HHS issues guidelines requiring applicants for NIH grants to address "the appropriate inclusion of women and minorities in clinical research."

# 1995

• February 23: Olympic gold medal diver Greg Louganis discloses that he has AIDS.

• March 26: Eric Lynn Wright, a.k.a. rapper Eazy-E, dies from an AIDS-related illness, one month after being diagnosed.

• In June, FDA approves the first *protease inhibitor*. This ushers in a new era of *highly active antiretroviral therapy* (HAART ).

• June 14: President Clinton issues an Executive Order [PDF, 149 KB] establishing his Presidential Advisory Council on HIV/AIDS. The Council meets for the first time on July 28.

• June 27: The National Association of People With AIDS launches the first National HIV Testing Day.

• July 14: CDC issues the first guidelines to help healthcare providers prevent opportunistic infections in people infected with HIV.

• September 22: CDC reviews Syringe Exchange Programs -- United States, 1994-1995. The National Academy of Sciences concludes that syringe exchange programs should be regarded as an effective component of a comprehensive strategy to prevent infectious disease.

• By October 31, 500,000 cases of AIDS have been reported in the U.S.

# 1996

In this year, the number of new AIDS cases diagnosed in the U.S. declines for the first time since the beginning of the epidemic. The International AIDS Vaccine Initiative (IAVI) forms to speed the search for an effective HIV vaccine.

January 1: UNAIDS (the Joint United Nations Programme on HIV/AIDS) begins operations. It is established to advocate for global action on the epidemic and to coordinate HIV/AIDS efforts acros the UN system.

FDA approves:

• the first HIV home testing and collection kit (May 14)

• a viral load test, which measures the level of HIV in the blood (June 3)

• the first non-nucleoside reverse transcriptas inhibitor (NNRTI) drug, nevirapine (June 21)

• July 7–12: In Vancouver, the 11th International AIDS Conference highlights the effectiveness of highly active antiretroviral therapy (HAART), creating a period of optimism.

• In October, the AIDS Memorial Quilt is displayed in its entirety for the last time. It covers the entire National Mall in Washington, DC.

• December 30: *TIME Magazine* names HIV/AIDS researcher Dr. David Ho as its "Man of the Year" for his work on highly active antiretroviral therapy. Ho advocates for a new strategy of treating HIV – "hit early, hit hard," in which patients are placed on new, more aggressive treatment regimens earlier in the course of their infection in hopes of keeping them healthier longer.

In this year, highly active antiretroviral therapy (HAART) becomes the new standard of HIV care.
CDC reports the first substantial decline in AIDS deaths in the United States. Due largely to the use of HAART, AIDS-related deaths in the U.S. decline by 47% compared with the previous year.

• May 18: President Clinton announces that the goal of finding an effective vaccine for HIV in 10 years will be a top national priority, and calls for the creation of an AIDS vaccine research center at NIH. (He dedicates the Dale and Betty Bumpers Vaccine Research Center on June 9, 1999.)

• September 26: FDA approves Combivir<sup>®</sup>, a combination of two antiretroviral drugs in one tablet, which makes it easier for people living with HIV to take their medications.

• November 21: The U.S. Congress enacts the Food and Drug Administration Modernization Act (FDAMA) of 1997, codifying an accelerated drugapproval process and allowing dissemination of information about off-label uses of drugs.

• UNAIDS estimates that 30 million adults and children worldwide have HIV, and that, each day, 16,000 people are newly infected with the virus.

• As a greater number of people begin taking *protease inhibitors*, resistance to the drugs becomes more common, and drug resistance emerges as an area of grave concern within the AIDS community.

## 1998

CDC reports that African Americans account for 49% of U.S. AIDS-related deaths. AIDS-related mortality for African Americans is almost 10 times that of Whites and three times that of Hispanics.
In March, African-American leaders, including members of the Congressional Black Caucus (CBC), are briefed on the highly disproportionate impact of HIV and AIDS in their communities. They develop a "Call to Action," requesting that the President and Surgeon General declare HIV/AIDS a "State of Emergency" in the community.

• In October, President Clinton declares AIDS to be a "severe and ongoing health crisis" in African-American and Hispanic communities in the United States. He announces a special package of initiatives aimed at reducing the impact of HIV/AIDS on racial and ethnic minorities.

• With the leadership of the CBC, Congress funds the Minority AIDS Initiative [PDF, 126 KB]. An unprecedented \$156 million is invested to improve the nation's effectiveness in preventing and treating HIV/AIDS in African-American, Hispanic, and other minority communities.

• April 20: HHS Secretary Donna Shalala determines that needle-exchange programs (NEPs) are effective and do not encourage the use of illegal drugs, but the Clinton Administration does not lift the ban on use of federal funds for NEPs.

• April 24: CDC issues the first national treatment guidelines for the use of antiretroviral therapy

[PDF, 2.86 MB] in adults and adolescents with HIV. • In June, UNAIDS reports [PDF, 2.34 MB] that the number of women living with HIV/AIDS in sub-Saharan Africa now exceeds that of men.

• June 25: The U.S. Supreme Court rules that the Americans with Disabilities Act covers those in earlier stages of HIV disease, not just those who have developed AIDS.

• November 12: The U.S. Congress enacts the Ricky Ray Hemophilia Relief Fund Act, [PDF, 184 KB] honoring the Florida teenager who was infected with HIV through contaminated blood products. The Act authorizes payments to individuals with *hemophilia* and other blood-clotting disorders who were infected with HIV by unscreened blood-clotting agents between 1982 and 1987. Ricky Ray died of AIDSrelated illness on December 13, 1992 at age 15, and Robert Ray died on October 20, 2000 at age 22.

### 1999

• The Congressional Hispanic Caucus, with the Congressional Hispanic Caucus Institute, convenes Congressional hearings on the impact of HIV/AIDS on the Latino community.

• WHO announces that HIV/AIDS has become the fourth biggest killer worldwide and the number one killer in Africa. The organization estimates that 33 million people are living with HIV worldwide, and that 14 million have died of AIDS.

• In March, VaxGen, a San Francisco-based biotechnology company, begins conducting the first human vaccine trials in a developing country (Thailand).

• In May, activist Phill Wilson founds the Black AIDS Institute. The Institute's mission is "to stop the AIDS pandemic in Black communities by engaging and mobilizing Black institutions and individuals in efforts to confront HIV." Its motto: "*Our People, Our Problem, Our Solution.*"

• July 19: President Clinton announces the formation of the "Leadership and Investment in Fighting an Epidemic" (LIFE) Initiative [PDF, 88 KB], which will provide funding to address the global HIV epidemic.

• **December 10:** CDC releases a new HIV case definition to help state health departments expand their HIV surveillance efforts and more accurately track the changing course of the epidemic.

# 2000

• January 10: The UN Security Council meets to

discuss the impact of AIDS on peace and security in Africa. This marks the first time that the Council discusses a health issue as a threat to peace and security.

• January 27: In his State of the Union address, President Clinton announces the launch of the Millennium Vaccine Initiative to create incentives for developing and distributing vaccines against HIV, TB, and malaria.

• April 30: The Clinton Administration declares that HIV/AIDS is a threat to U.S. national security.

• May 10: President Clinton issues an Executive Order to assist developing countries in importing and producing generic HIV treatments.

• In July, UNAIDS, WHO, and other global health groups announce a joint initiative with five major pharmaceutical manufacturers to negotiate reduced prices for HIV/AIDS drugs in developing countries.

• August 19: The U.S. Congress enacts the Global AIDS and Tuberculosis Relief Act of 2000. [PDF, 2.1 MB]

• In September, as part of its Millennium Declaration, the UN adopts the Millennium Development Goals, which include a specific goal of reversing the spread of HIV/AIDS, malaria, and TB.

# 2001

• February 7 marks the first annual National Black HIV/AIDS Awareness Day in the U.S.

• April 23: General Colin Powell, the newly appointed U.S. Secretary of State, reaffirms the U.S. statement that HIV/AIDS is a national security threat.

• May 18 is the first annual observance of HIV Vaccine Awareness Day.

• June 25-27: The UN General Assembly holds its first Special Session on AIDS (UNGASS) and passes the UNGASS Declaration of Commitment and the ILO

(International Labor Organization) Code of Practice on HIV/AIDS in the Workplace [PDF, 127 KB]. The meeting also calls for the creation of an international "global fund" to support efforts by countries and organizations to combat the spread of HIV through prevention, care, and treatment, including the purchase of HIV medications.

• November 14: The World Trade Organization announces the Doha Declaration, which affirms the rights of developing countries to buy or

• After generic drug manufacturers offer to produce discounted, generic forms of HIV/AIDS drugs for developing countries, several major pharmaceutical manufacturers agree to offer further reduced drug prices to those countries.

manufacture generic medications to meet public health crises such as HIV/AIDS.

• HRSA begins focusing on individuals with HIV disease who know their status and are not receiving HIV-related services. HRSA instructs its grantees to address this population's "unmet need" for services.

• CDC announces a new HIV Prevention Strategic Plan to cut annual HIV infections in the U.S. by half within five years.

# 2002

• January 22: The Global Fund to Fight AIDS,

Tuberculosis and Malaria, a partnership between governments, civil society organizations, the private sector, and affected communities, is established.

• April 22-24: The Global Fund approves its first round of grants to governments and private-sector organizations in the developing world. The grants total \$600 million for two-year projects.

• June 25: The United States announces a framework that will allow poor countries unable to produce pharmaceuticals to gain greater access to drugs needed to combat HIV/AIDS, malaria, and other public health crises.

• In July, UNAIDS reports that HIV/AIDS is now by far the leading cause of death in sub-Saharan Africa, and the fourth biggest global killer. Average life expectancy in sub-Saharan Africa falls from 62 years to 47 years as a result of AIDS.

• July 7-12: The 14th International AIDS Conference is held in Barcelona, Spain. Dozens of countries report they are experiencing serious HIV/AIDS epidemics, and many more are on the brink.

• In September, the U.S. National Intelligence Council releases *Next Wave of the Epidemic* [PDF, 3.34 MB], a report focusing on HIV in India, China, Russia, Nigeria, and Ethiopia.

• November 7: FDA approves the first rapid HIV diagnostic test kit for use in the United States that provides results with 99.6% accuracy in as little as 20 minutes. Unlike other antibody tests for HIV, this blood test can be stored at room temperature, requires no specialized equipment, and may be used outside of traditional laboratory or clinical settings, allowing more widespread use of HIV testing.

• Worldwide, 10 million young people, aged 15-24, and almost 3 million children under 15 are living with HIV. During this year, approximately 3.5 million new infections will occur in sub-Saharan Africa, and the epidemic will claim the lives of an estimated 2.4 million Africans.

## 2003

• CDC calculates that 27,000 of the estimated 40,000 new infections that occur each year in the U.S. result from transmission by individuals who do not

know they are infected.

• January 28: President George W. Bush announces the creation of the United States President's Emergency Plan For AIDS Relief (PEPFAR) in his State of the Union address. PEPFAR is a \$15 billion, 5-year plan to combat AIDS, primarily in countries with a high burden of infections.

• February 23: VaxGen, a San Francisco-based biotechnology company, announces that its AIDSVAX vaccine trial failed to reduce overall HIV infection rates among those who were vaccinated.

• March 31: The Bill and Melinda Gates Foundation awards a \$60 million grant to the International Partnership for Microbicides to support research and development of microbicides to prevent transmission of HIV.

• April 18: CDC announces Advancing HIV Prevention: New Strategies for a Changing Epidemic, a new prevention initiative that aims to reduce barriers to early diagnosis and increase access to, and utilization of, quality medical care, treatment, and ongoing prevention services for those living with HIV.

• May 6: The "Group of Eight" (G8) Summit includes a special focus on HIV/AIDS and announcements of new commitments [PDF, 854 KB] to the Global Fund to Fight AIDS, Tuberculosis and Malaria. G8 members make up most of the world's largest economies and include: Canada, France, Germany, Italy, Japan, Russia, the United Kingdom, and the United States.

• October 6: Randall Tobias is sworn in as the first Ambassador at Large and U.S. Global AIDS Coordinator to oversee PEPFAR.

• October 15 marks the first annual National Latino AIDS Awareness Day in the U.S.

• October 23: The William J. Clinton Foundation secures price reductions for HIV/AIDS drugs from

generic manufacturers, to benefit developing nations.

• **December 1:** WHO announces the "3 by 5" initiative, to bring treatment to 3 million people by 2005.

# 2004

• In January, the U.S. Congress authorizes the first \$350 million for the United States President's Emergency Program for AIDS Relief (PEPFAR).

• In February, UNAIDS launches The Global Coalition on Women and AIDS to raise the visibility of the epidemic's impact on women and girls around the world.

• March 26: FDA approves the use of oral fluid samples with a rapid HIV diagnostic test kit that provides the result in approximately 20 minutes.

• May 17: FDA issues a guidance document for expedited approval of low cost, safe, and effective co-packaged and fixed-dose combination HIV therapies so that high-quality drugs can be made available in Africa and developing countries around the world under PEPFAR.

• June 10: Leaders of the "Group of Eight" (G8) Summit (Canada, France, Germany, Italy, Japan, Russia, the United Kingdom, and the United States) call for the creation of a "Global HIV Vaccine Enterprise," a consortium of government and private-sector groups designed to coordinate and accelerate research efforts to find an effective HIV vaccine.

# 2005

• January 6: Former South African president Nelson Mandela announces that his son, Makgatho Mandela, has died of AIDS-related illness at age 54. Mandela urges South Africans to treat AIDS as an "ordinary disease," rather than a "curse." He also asks families to speak openly about the toll of the disease, in order to break down the taboos associated with HIV/AIDS.

• January 26–30: During its annual meeting, the World Economic Forum approves a set of new priorities, including one with a focus on addressing HIV/AIDS in Africa and other hard-hit regions.

• January 26: WHO, UNAIDS, the U.S. Government, and the Global Fund to Fight AIDS, Tuberculosis and Malaria announce results of joint efforts to increase the availability of antiretroviral drugs in developing countries. An estimated 700,000 people have been reached by the end of 2004.

• April 3: Biologists announce that they have discovered that the plagues of the Middle Ages made around 10% of Europeans—particularly those in Scandinavia and Russia—resistant to HIV.

• May 19 is the first annual National Asian and Pacific Islander HIV/AIDS Awareness Day in the U.S.

## 2006

• March 10 is the first annual National Women and Girls HIV/AIDS Awareness Day in the U.S.

• March 20 is the first annual observance of National Native HIV/AIDS Awareness Day in the U.S.

• May 2–6: NIH's Office of AIDS Research sponsors Embracing Our Traditions, Values, and Teachings: Native Peoples of North America HIV/AIDS Conference, in Anchorage, Alaska. The conference involves nearly 1,000 participants from the American Indian, Alaska Native, Native Hawaiian, First Nations, and U.S. Territorial Pacific Islander communities.

• May 25: Scientists announce they have spotted the signs of an HIV-like virus in chimpanzees in

southern Cameroon. The discovery bolsters the theory that the first people to contract HIV did so through contact with infected blood from wild chimps in the jungle.

• May 31: The UN convenes a follow-up meeting and issues a progress report on the implementation of the *Declaration of Commitment* on *HIV/AIDS*.

• August 11: President George W. Bush appoints Dr. Mark Dybul as the Ambassador at Large and U.S. Global AIDS Coordinator to oversee the President's Emergency Plan for AIDS Relief (PEPFAR). Dybul replaces former Ambassador Randall Tobias. He is sworn in on October 10.

• August 16: WHO reports that the number of people receiving HIV antiretroviral therapy in sub-Saharan Africa has surpassed 1 million for the first time—a 10fold increase in treatment access in the region since December 2003. The increase is a result of country spending, as well as support from PEPFAR, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the World Bank, pharmaceutical companies, and other bilateral donors.

September 22: CDC releases revised HIV testing recommendations for healthcare settings, recommending routine HIV screening for all adults, aged 13-64, and yearly screening for those at high risk.
December 13: NIH announces the early end of two clinical trials of adult male circumcision after a review of trial data reveals that medically performed circumcision reduces a man's risk of acquiring HIV through heterosexual intercourse by up to 53%.

## 2007

• March 28: WHO officially recommends circumcision as a way to prevent heterosexual transmission of the AIDS virus, setting the stage for donor agencies to begin paying for the operation.

• May 9: The Clinton Foundation announces it has negotiated deep price reductions for generic versions of costly, second-line AIDS drugs needed when the original medicines fail, as well as for less toxic, easier-to-use first-line medicines combined in a pill that can be taken once a day.

• May 30: In an attempt to increase the number of people taking HIV tests, WHO and UNAIDS issue new guidance recommending "provider-initiated" HIV testing in healthcare settings.

• September 21: Trials of the most promising HIV vaccine to date [STEP (HVTN 502) and Phambili (HVTN 503)] are halted after an independent Data and Safety Monitoring Board determines that the vaccine is not protecting study subjects against HIV infection. A subsequent study in 2012 will find that the vaccine actually increased participants' risk of contracting HIV, although the reasons for this are not clear.

• In October, CDC launches *Prevention IS Care* (PIC), a social-marketing campaign designed for healthcare providers who deliver care to people living with HIV.

• November 13: CDC reports that four transplant recipients have contracted both HIV and hepatitis C from an organ donor—the first known cases in more than a decade of the virus being spread by organ transplants. This leads to a call for more intensive testing of donor organs, which may have been infected too recently for HIV to be detected on standard tests.

• November 20: WHO and UNAIDS announce [PDF, 1.63 MB] improved surveillance data showing global HIV prevalence has levelled off, and is lower than previously believed (33 million instead of 40 million). The data also indicate declines in the numbers of new infections and people dying from AIDS-related

illnesses, due in part to HIV-prevention programs and antiretroviral therapy.

• CDC reports over 565,000 people have died of AIDS in the U.S. since 1981.

## 2008

• January 8: The Journal of the American Medical Association reports that the incidence of HIV infection among gay men in the U.S. is increasing, following an encouraging period of decline. Between 2001–2006, new HIV diagnoses in gay men under age 30 rose 32%. Among black and Hispanic men, the figure was 34%. Most troubling, the number of new diagnoses among the youngest men in the study (ages 13–19) doubled.

• June 23: Dr. Eric Goosby is sworn in as Ambassador at Large and U.S. Global AIDS Coordinator to oversee the President's Emergency Plan for AIDS Relief (PEPFAR). He replaces Dr. Mark Dybul.

• July 25: A large international study finds evidence that people taking HIV treatment can now expect to live into their 60s and beyond. Researchers report that a 20-year-old person living with HIV who starts treatment with a CD4 cell count above 200 cells/mm3 can expect to live to be 70.

• July 29: According to a report [PDF, 1.42 MB] released by the Black AIDS Institute, the HIV/ AIDS epidemic among African-Americans in some parts of the U.S. is as severe as in parts of Africa. The report, *Left Behind - Black America: A Neglected Priority in the Global AIDS Epidemic*, calls for greater government investment in HIV/AIDS prevention, testing, and treatment programs in hard-hit U.S. regions.

• July 31: President George W. Bush signs legislation reauthorizing PEPFAR for an additional five years for up to \$48 billion. The bill contains a rider that

lifts the blanket ban on HIV-positive travelers to the U.S., and gives HHS the authority to admit people living with HIV/AIDS on a case-by-case basis.

• August 6: CDC releases new domestic HIV incidence estimates that are substantially higher than previous estimates (56,300 new infections per year vs. 40,000). The new estimates do not represent an actual increase in the numbers of HIV infections, but reflect a more accurate way of measuring new infections. A separate analysis suggests that the annual number of new infections was never as low as 40,000 and that it has been roughly stable since the late 1990s.

• September 11: A CDC study of people newly infected with HIV in the U.S. confirms that the majority of new cases occur among gay and bisexual men and that African-Americans are most at risk. But the data show that most new infections of white gay and bisexual men occur when the men are in their 30s and 40s, while black gay and bisexual men are more likely to be infected in their teens and 20s.

• September 18 marks the first observance of National HIV/AIDS and Aging Awareness Day.

• September 27 marks the first observance of National Gay Men's HIV/AIDS Awareness Day.

• October 1: An international team of researchers announces that HIV in humans may have originated as early as the 1880s. Findings from the new study suggest that the virus most likely started circulating among humans in sub-Saharan Africa sometime between 1884 and 1924 and may have been triggered by rapid urbanization in west-central Africa.

• October 1: Project Masiluleke ("lend a helping hand") is launched in South Africa. It is the first program to use free text messages to overcome stigma and promote HIV testing and treatment. The messages include the number for the National AIDS Helpline and prompt recipients to call back the sender. The program triples the rate of calls to the helpline and surpasses the 1 billion mark in call backs within 3 years.

• October 6: The Nobel Prize in medicine is awarded to two French virologists, Françoise Barré-Sinoussi, and Luc A. Montagnier, for their 1983 discovery of HIV, the virus that causes AIDS.

### 2009

• Newly elected President Barack Obama calls for the development of the first National HIV/AIDS Strategy for the United States.

• In February, the District of Columbia Health Department's HIV/AIDS, Hepatitis, STD, and TB Administration reports [PDF, 7.12 MB] that Washington, DC has a higher rate of HIV (3% prevalence) than West Africa—enough to describe it as a "severe and generalized epidemic."

• April 7: The White House and CDC launch the Act Against AIDS campaign, a multiyear, multifaceted communication campaign designed to reduce HIV incidence in the United States. CDC also launches the Act Against AIDS Leadership Initiative (AAALI), to harness the collective strength and reach of traditional, longstanding African-American institutions to increase HIV-related awareness, knowledge, and action within Black communities across the U.S.

• May 5: President Obama launches the Global Health Initiative (GHI), a six-year, \$63 billion effort to develop a comprehensive approach to addressing global health in low- and middleincome countries. The United States President's Emergency Plan for AIDS Relief (PEPFAR) will serve as a core component.

• June 8 marks the first annual recognition of Caribbean

#### American HIV/AIDS Awareness Day.

• August 17: The Department of Veterans Affairs (VA) moves to increase the number of veterans getting HIV tests by dropping the requirement for written consent (verbal consent is still required).

• October 30: President Obama announces that his administration will officially lift the HIV travel and immigration ban in January 2010 by removing the final regulatory barriers to entry. The lifting of the travel ban occurs in conjunction with the announcement that the XIX International AIDS Conference will return to the United States for the first time in more than 20 years.

• November 24: UNAIDS reports that there has been a significant decline (-17%) in new HIV infections in the past decade. East Asia, however, has seen a dramatic 25% increase in infections over the same period.

• December 16: The U.S. Congress enacts legislation [PDF, 1.08 MB] that modifies the ban on the use of federal funds for needle-exchange programs. When applicable, federal funds may be used for personnel, equipment, syringe disposal services, educational materials, communication, marketing, and evaluation activities. On December 16, 2011, Congress reinstates the ban.

## 2010

• January 4: The U.S. Government officially lifts the HIV travel and immigration ban.

• March 23: President Obama signs the Patient Protection and Affordable Care Act [PDF, 2.72 KB], which expands access to care and prevention for all Americans—but offers special protections for those living with chronic illnesses, like HIV, that make it difficult for them to access or afford healthcare.

• July 13: The Obama Administration releases the

first comprehensive National HIV/AIDS Strategy for the United States.

• July 19: The results of the Centre for the AIDS Programme of Research in South Africa's (CAPRISA) 004 study of antiretroviral-based vaginal microbicides are released at the 18th International AIDS Conference in Vienna, Austria. The study shows the microbicides to be safe and effective in reducing risks of new HIV infections among women by 39%. Women who use the microbicides as directed have even higher rates of protection (54%) against HIV infection.

• September 20-22: The UN convenes a summit to accelerate progress toward the 2015 Millennium Development Goals.

• Also in September, WHO, UNAIDS, and UNICEF publish their annual Universal Access report for low- and middle-income countries. The report shows an estimated 5.25 million people were receiving antiretroviral therapy in 2009, and an estimated 1.2 million people started treatment that same year – the largest annual increase yet recorded.

• November 23: NIH announces the results of the iPrEx study, showing that a daily dose of HIV drugs reduced the risk of HIV infection among HIV-negative men who have sex with men by 44%, supporting the concept of *pre-exposure prophylaxis* (PrEP) in a targeted population.

# 2011

• March 23: AIDS activist and award-winning actress Elizabeth Taylor dies. One of the first celebrities to advocate on behalf of people living with HIV and AIDS, Taylor was the founding national chairman of amfAR (American Foundation for AIDS Research), a nonprofit organization that supports AIDS research, HIV prevention, treatment education, and advocates for AIDS-related public policy.

• In April, public debate begins on whether the longstanding ban on transplants of HIV-infected organs should be dropped.

• June 8: HHS Secretary Sebelius hosts "Commemorating 30 Years of Leadership in the Fight Against HIV/AIDS." Watch the Secretary's speech.

• June 8–10: Over 3,000 people participate in the United Nation's (UN) High-Level Meeting on HIV/AIDS in New York. The session recognizes critical milestones, including three decades of the pandemic and the 10-year anniversary of the 2001 UN General Assembly Special Session on HIV/AIDS and the resulting Declaration of Commitment. At the meeting, the U.S. joins with other partners in launching a global plan to eliminate mother-tochild transmission of HIV and keep mothers alive.

• July 13 marks the one-year anniversary of the White House National HIV/AIDS Strategy. The White House release a video: "President Obama's National HIV/AIDS Strategy" and the "National HIV/AIDS Strategy: Implementation Plan Update" [PDF, 387 KB].

• July 13: A new CDC study (TDF2) [PDF, 130 KB] and a separate clinical trial (the Partners PrEP study) [PDF, 144 KB] provide the first evidence that a daily oral dose of antiretroviral drugs used to treat HIV infection can also prevent new infections in individuals exposed to HIV through heterosexual sex.

• AIDS Action merges with the National AIDS Fund to form AIDS United.

• July 17-20: At the International AIDS Society's Conference on HIV Pathogenesis, Treatment, and Prevention in Rome, scientists announce that two studies have confirmed that individuals taking daily antiretroviral drugs experienced infection rates more than 60% lower than those on a placebo.

• In September, the Office of National AIDS Policy begins to convene a series of five regional dialogues to focus attention on critical implementation issues for the National HIV/AIDS Strategy.

• September 30: A coalition of community-based organizations joins with the International AIDS Society to kick off the first Road to AIDS 2012 Town Hall meeting in San Francisco. This is the first of 15 meetings to be held across the country, leading up to the XIX International AIDS Conference (AIDS 2012).

• November 8: Secretary of State Hillary Rodham Clinton shares the U.S. Government's bold new vision of creating an AIDS-free generation and speaks about the remarkable progress made in 30 years of fighting AIDS.

• December 1: At the ONE Campaign and (RED) event in Washington, DC, President Obama marks World AIDS Day by announcing accelerated efforts to increase the availability of treatment to people living with HIV/AIDS in the United States. He challenges the global community to deliver funds to The Global Fund to Fight AIDS, Tuberculosis and Malaria, and calls on Congress to keep its past commitments intact. He calls on all Americans to keep fighting to end the epidemic.

• **December 1:** Lead federal agencies release implementation plans in support of the U.S. National HIV/AIDS Strategy.

• **December 23:** The journal *Science* announces that it has chosen the HPTN 052 study as its 2011 Breakthrough of the Year.

## 2012

• March 13: Researchers from the University of New

South Wales in Australia find that people living with HIV who are taking antiretroviral therapy have an increased risk of cardiovascular disease.

• March 27: HHS issues new HIV treatment

guidelines recommending treatment for all HIVinfected adults and adolescents, regardless of CD4 count or viral load.

• June 20: The Washington, DC, Department of Health releases a study showing a drop in the overall number of new AIDS cases in the District over four years and improvements in getting infected people into care quickly. But the progress is uneven: HIV infection rate for heterosexual African-American women in the District's poorest neighborhoods nearly doubled in two years, from 6.3% to 12.1%.

• July 1: The Kaiser Family Foundation and the *Washington Post* release a joint survey of the American public's attitudes, awareness, and experiences related to HIV and AIDS. The survey finds that roughly a quarter of Americans do not know that HIV cannot be transmitted by sharing a drinking glass—almost exactly the same share as in 1987.

• July 3: The FDA approves the first at-home HIV test that will let users learn their HIV status right away.

• July 16: The FDA approves the use of Truvada<sup>®</sup> for pre-exposure prophylaxis (PrEP). Adults who do not have HIV, but who are at risk for infection, can now take this medication to reduce their risk of getting the virus through sexual activity.

• July 22-27: The XIX International AIDS Conference (AIDS 2012) is held in Washington, DC—the first time since 1990 that the conference has been held in the United States. Conference organizers had refused to convene the event in the U.S. until the federal government lifted the ban on HIV-positive travelers entering the country.

• During AIDS 2012, the AIDS Memorial Quilt is displayed in its entirety in Washington, DC, for the first time since 1996. Volunteers have to rotate nearly 50,000 panels to ensure that the entire work is displayed.

## 2013

• The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) celebrates its 10th anniversary.

• March 4: NIH-funded scientists announce the first well-documented case of an HIV-infected child, designated as "the Mississippi Baby," who appears to have been functionally cured of HIV infection (i.e., no detectable levels of virus or signs of disease, even without antiretroviral therapy).

• June 2: The New York Times runs two articles which focus on middle-aged people living with HIV: The Faces of H.I.V. in New York in 2013 and 'People Think It's Over': Spared Death, Aging People With H.I.V. Struggle to Live.

• June 5: NMAC releases *RISE Proud: Combating HIV Among Black Gay and Bisexual Men* [PDF, 1.4 MB], an action plan to mitigate the impact of HIV on black gay and bisexual men.

• June 18: Secretary of State John Kerry announces that, thanks to direct PEPFAR support, more than 1 million infants have been born HIV-free since 2003.

• July 3: Researchers report that two HIV-positive patients in Boston who had bone-marrow transplants for blood cancers have apparently been virus-free for weeks since their antiretroviral drugs were stopped.

• July 13: President Obama issues an Executive Order directing federal agencies to prioritize supporting the HIV care continuum as a means of implementing the National HIV/AIDS Strategy. The HIV Care Continuum Initiative aims to accelerate efforts to improve the percentage of people living with HIV who move from testing to treatment and—ultimately—to viral suppression.
In October, the National Latino AIDS Action Network —a diverse coalition of communitybased organizations, national organizations, state and local health departments, researchers and concerned individuals—publishes the National Latino/Hispanic HIV/AIDS Action Agenda [PDF, 4.1 MB] to raise awareness, identify priorities, and issue specific recommendations to address the impact of the epidemic in Hispanic/Latino communities.

• November 1: *Dallas Buyers Club*—a film about an HIV-positive man who smuggled unapproved HIV drugs from Mexico to meet the demands of people who were dying of AIDS—is released to wide critical acclaim. The film, which is based on the true story of Texas electrician Ron Woodroof, goes on to win three Academy Awards. Woodroof died of AIDS-related illness on September 12, 1992.

• November 21: President Obama signs the HIV Organ Policy Equity (HOPE) Act, which will allow people living with HIV to receive organs from other infected donors. The HOPE Act has the potential to save the lives of about 1,000 HIV-infected patients with liver and kidney failure annually.

• December 5: Nelson Mandela —South African anti-apartheid leader, political prisoner, and national President from 1994 to 1999—dies at the age of 95. After his son, Makgatho, died of AIDS-related causes in 2005, Mandela spent the remainder of his postpresidential career working to address the AIDS epidemic in South Africa, which is home to the largest number of people living with HIV (~6.8 million) in the world. At the end of 2012, UNAIDS estimates that, worldwide, 2.3 million people were newly infected with HIV during the year, and 1.6 million people died of AIDS. Approximately 35.3 million people around the world are now living with HIV, including more than 1.2 million Americans [PDF, 477 KB].
UNAIDS also announces that new HIV infections have dropped more than 50% in 25 low- and middleincome countries, and the number of people getting antiretroviral treatment has increased 63% in the past

2014

two years.

• January 1: Major provisions of the Affordable Care Act designed to protect consumers go into effect. Insurers are now barred from discriminating against customers with pre-existing conditions, and they can no longer impose annual limits on coverage—both key advances for people living with HIV/AIDS.

• January 2: News sources report that the two Boston patients believed to have been cured of HIV after undergoing treatment for cancer have relapsed.

• In March, the UN Commission on the Status of Women releases a report [PDF, 563 KB] on the challenges and achievements of implementing the Millennium Development Goals (MDGs) for women and girls. The Commission concludes that progress on MDG6 (*Combating HIV/AIDS, Malaria, and Other Diseases*) has been limited, given that the number of women living with HIV globally continues to increase. The report notes several key challenges: adolescent/young women's particular vulnerability to HIV; the need to increase access to healthcare services; and the challenges of structural gender inequalities, stigma, discrimination, and violence. • March 4: European researchers announce the results of the first phase of the PARTNER Study, an observational study focusing on the risk of sexual HIV transmission when an HIV-positive person is on treatment. The study found that no HIV-positive partner who was undergoing antiretroviral therapy and had an undetectable viral load had transmitted HIV.

• March 24: Douglas Brooks is appointed as the new Director of the White House Office of National AIDS Policy (ONAP). He is the first African-American and the first HIV-positive person to hold the position.

• April 4: Dr. Deborah Birx is sworn in as Ambassador at Large and U.S. Global AIDS Coordinator to oversee the President's Emergency Plan for AIDS Relief (PEPFAR). She replaces Dr. Eric Goosby.

• July 10: NIH announces that the "Mississippi baby" now has detectable levels of HIV after more than two years of showing no evidence of the virus.

• July 17: Malaysia Airlines' Flight MH17, en route from Amsterdam to Kuala Lumpur, is shot down over conflict-ridden Ukraine, killing all 298 people aboard—including six prominent scientists and AIDS activists on their way to the 20th International AIDS Conference (AIDS 2014) in Melbourne, Australia.

• July 20-25: AIDS 2014 draws nearly 14,000 delegates from over 200 nations. One key message of the conference is that a one-size-fits-all approach may not be suitable for all settings, [PDF, 4.6 MB] especially given the diversity of the epidemic's geographical hotspots and key populations. Interventions and policies will require target-based strategies and greater support of key populations, especially in countries where discriminatory policies and legislation are hindering prevention and treatment efforts.

• September 9: The Pew Charitable Trust reports that

southern states are now the epicenter of HIV/AIDS in the U.S.

• October 9: CDC releases a new report that finds gaps in care and treatment among Latinos diagnosed with HIV.

• November 25: CDC announces that only 30% of Americans with HIV had the virus under control in

2011. Approximately two-thirds of those whose virus was out of control have been diagnosed but are no longer in care.

# 2015

• January 8: A review of multiple studies of South African women indicates that using Depo Provera<sup>®</sup>, an injectable contraceptive, may increase women's chances of contracting HIV by 40%.

• February 23: CDC's annual *HIV Surveillance Report* [PDF, 2.8 MB], indicates that HIV diagnosis rates in the U.S. remained stable between 2009-2013, but men who have sex with men, young adults, racial/ ethnic minorities, and individuals living in the South continue to bear a disproportionate burden of HIV.

• February 23: CDC announces that more than 90% of new HIV infections in the United States could be prevented by diagnosing people living with HIV and ensuring they receive prompt, ongoing care and treatment.

• February 25: Indiana state health officials announce an HIV outbreak linked to injection drug use [PDF, 59 KB] in the southeastern portion of the state. By the end of the year, Indiana will confirm 184 new cases of HIV linked to the outbreak.

• May 8: HHS announces plans to amend the federal rules covering organ transplants to allow the recovery of transplantable organs from HIV positive donors. The new regulations will provide

a framework for clinical studies on transplanting organs from HIV-positive donors to HIV-positive recipients.

• May 27: Results from the Strategic Timing of AntiRetroviral Treatment (START ) study indicate that HIV-positive individuals who start taking antiretroviral drugs before their CD4+ cell counts decrease have a considerably lower risk of developing AIDS or other serious illnesses. Subsequent data releases show that early therapy for people living with HIV also prevents the onset of cancer, cardiovascular disease, and other non-AIDS related diseases.

• June 30: WHO certifies that Cuba is the first nation to eliminate mother-to-child transmission of both HIV and syphilis.

• July 14: UNAIDS announces that the targets for Millennium Development Goal #6 — halting and reversing the spread of HIV—have been achieved and exceeded 9 months ahead of the schedule set in 2000.

• July 20: Researchers report that antiretroviral therapy is highly effective at preventing sexual transmission of HIV from a person living with HIV to an uninfected heterosexual partner, when the HIV-positive partner is virally suppressed. The finding comes from the decade-long HPTN 052 clinical trial.

• July 30: The White House launches the National HIV/AIDS Strategy: Updated to 2020 [PDF, 2.2 MB]. The updated Strategy retains the vision and goals of the original, but reflects scientific advances, transformations in healthcare access as a result of the Affordable Care Act, and a renewed emphasis on key populations, geographic areas, and practices necessary to end the domestic HIV epidemic.

#### • September 26: At a UN summit on the

Sustainable Development Goals, the United States announces new PEPFAR prevention and treatment targets [PDF, 640 KB] for 2016–2017. By the end of 2017, the U.S. will commit sufficient resources to support antiretroviral therapy for 12.9 million people, provide 13 million male circumcisions for HIV prevention, and reduce HIV incidence by 40% among adolescent girls and young women within the highest burdened areas of 10 sub-Saharan African countries.

• September 30: The WHO announces new treatment recommendations that call for all people living with HIV to begin antiretroviral therapy as soon after diagnosis as possible. WHO also recommends daily oral *PrEP* as an additional prevention choice for those at substantial risk for contracting HIV. WHO estimates the new policies could help avert more than 21 million deaths and 28 million new infections by 2030.

• October 20: Greater Than AIDS launches a new campaign, Empowered: Women, HIV and Intimate Partner Violence to bring more attention to issues of relationship violence and provide resources for women who may be at risk of, or dealing with, abuse and HIV.

• November 17: Actor Charlie Sheen announces his HIV-positive status in a nationally televised interview. Significant public conversation about HIV follows his disclosure. Other celebrities who disclose their HIVpositive status in 2015 are rapper, performance artist, and poet Mykki Blanco and former child TV star Danny Pintauro.

• November 24: UNAIDS releases its 2015 World AIDS Day report [PDF, 27 MB], which finds that 15.8 million people were accessing antiretroviral treatment as of June 2015—more than doubling the number of people who were on treatment in 2010.

• November 30: amfAR announces its plan to establish the Institute for HIV Cure Research at the University of California, San Francisco. As the cornerstone of amfAR's \$100 million investment in cure research, the Institute will work to develop the scientific basis for an HIV cure by the end of 2020.

• December 1: The White House releases a Federal Action Plan [PDF, 772 KB] to accompany the updated National HIV/AIDS Strategy. The plan was developed by 10 federal agencies and the Equal Employment Opportunity Commission and contains 170 action items that the agencies will undertake to achieve the goals of the Strategy.

• December 6: CDC announces that annual HIV diagnoses in the U.S. fell by 19% from 2005 to 2014. There were steep declines among heterosexuals, people who inject drugs, and African-Americans (especially black women), but trends for gay/bisexual men varied by race/ethnicity. Diagnoses among white gay/bisexual men decreased by 18%, but they continued to rise among Latino gay/bisexual men (+24%) and black gay/bisexual men (+22%), although the increase for the latter leveled off since 2010.

• **December 19:** Partly in response to the HIV outbreak in Indiana, which is linked to injection drug use, Congress modifies restrictions that prevented states and localities from spending federal funds for needle exchange programs.

• **December 21:** FDA announces it will lift its 30-yearold ban on all blood donations by men who have sex with men and institute a policy that allows them to donate blood if they have not had sexual contact with another man in the previous 12 months.

### 2016

• January 19: CDC reports that only 1 in 5 sexually

active high school students has been tested for HIV. An estimated 50% of young Americans who are living with HIV do not know they are infected.

• January 28: Researchers announce that an international study of over 1,900 patients with HIV who failed to respond to the antiretroviral drug tenofovir—a key HIV treatment medication—indicates that HIV resistance to the medication is becoming increasingly common.

• February 25: At the annual Conference on Retroviruses and Opportunistic Infections (CROI), researchers report that a man taking the HIV prevention pill Truvada<sup>®</sup> has contracted HIV—marking the first reported infection of someone regularly taking the drug.

• March 3: The White House Office of National AIDS Policy, the NIH Office of AIDS Research, and the National Institute of Mental Health cohost a meeting to address the issue of HIV stigma: *Translating Research to Action: Reducing HIV Stigma* 

*to Optimize HIV Outcomes*. Participants include researchers, policymakers, legal scholars, faith leaders, advocates, and people living with HIV.

• March 3: Pharmacy researchers report finding that women need daily doses of the antiviral medication Truvada<sup>®</sup> to prevent HIV infection, while men only need two doses per week due to differences in the way the drug accumulates in vaginal, cervical and rectal tissue.

• March 29: HHS releases new guidance [PDF, 960 KB] for state, local, tribal, and territorial health departments that will allow them to request permission to use federal funds to support syringe services programs (SSPs). The funds can now be used to support a comprehensive set of services, but they cannot be used to purchase sterile needles or syringes for illegal drug injection. • May 24: NIH and partners announce they will launch a large HIV vaccine trial in South Africa in November 2016, pending regulatory approval. This represents the first time since 2009 that the scientific community has embarked on an HIV vaccine clinical trial of this size.

• June 8-10: The UN holds its 2016 High-Level Meeting on Ending AIDS. UN member states pledge to end the AIDS epidemic by 2030, but the meeting is marked by controversy after more than 50 nations block the participation of groups representing LGBT people from the meeting. The final resolution barely mentions those most at risk for contracting HIV/ AIDS: men who have sex with men, sex workers, transgender people and people who inject drugs.

#### **Disclaimer and Acknowledgements**

The information contained in this timeline has been drawn from numerous sources, including (but not limited to) the Kaiser Family Foundation, AIDS Action (PDF), Australia's Albion Center (PDF), and the National Minority AIDS Council (NMAC).

We have also relied on material provided by the U.S. Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), the U.S. Food and Drug Administration (FDA), and the U.S. Health Resources and Services Administration (HRSA).

The timeline is presented for informational purposes only. AIDS.gov does not endorse any organization or viewpoint represented in entries drawn from non-Federal sources. Where possible, specific dates have been provided and events have been listed in chronological order. Entries without specific dates occurred in the year in which they are listed, but the order of those entries may not reflect the actual chronology of events.

Every attempt has been made to ensure that the information

contained in the timeline is accurate. Please send any corrections to <u>contact@aids.gov</u>.

https://www.hiv.gov/sites/default/files/aidsgov-timeline.pdf

#### **Chapter II. Overview**

#### D. Making A Difference 1. Supporting Someone Living with HIV

#### How Can You Help Someone Who Has Been Newly Diagnosed with HIV?

There are many things that you can do to help a friend or loved one who has been recently diagnosed with HIV:

- **Talk.** Be available to have open, honest conversations about HIV. Follow the lead of the person who is diagnosed with HIV. They may not always want to talk about it, or may not be ready. They may want to connect with you in the same ways they did before being diagnosed. Do things you did together before their diagnosis; talk about things you talked about before their diagnosis. Show them that you see them as the same person and that they are more than their diagnosis.
- **Listen.** Being diagnosed with HIV is life-changing news. Listen to your loved one and offer your support. Reassure them that HIV is a manageable health condition. There are medicines that can treat HIV and help them stay healthy.
- Learn. Educate yourself about HIV: what it is, how it is transmitted, how it is treated, and how people can stay healthy while living with HIV. Having a solid understanding of HIV is a big step forward in supporting your loved one. This website is a good place to begin to familiarize yourself with HIV. Have these resources available for your newly diagnosed friend if they want them. Knowledge is empowering, but keep in mind that your friend may not want the information right away.
- **Encourage treatment.** Some people who are recently diagnosed may find it hard to take that first step to HIV treatment. Your support and assistance may be helpful. By getting linked to HIV medical care early, starting <u>treatment with HIV medication</u> (called antiretroviral therapy or ART), adhering to medication, and staying in care, people with HIV can keep the virus under control, and prevent their HIV infection from progressing to AIDS. HIV treatment is

recommend for all people with HIV and should be started as soon as possible after diagnosis. Encourage your friend or loved one to see a doctor and start HIV treatment as soon as possible. If they do not have an HIV care provider, you can help them find one. There are programs that can provide HIV medical care or help with paying for HIV medications. Use HIV.gov's <u>HIV Testing Sites & Care Services Locator</u> to find a provider.

- **Support medication adherence**. It is important for people living with HIV to take their HIV medication every day, exactly as prescribed. Ask your loved one what you can do to support them in establishing a medication routine and sticking to it. Also ask what other needs they might have and how you can help them stay healthy. Learn more about <u>treatment adherence</u>.
- **Get support.** Take care of yourself and get support if you need it. Turn to others for any questions, concerns, or anxieties you may have, so that the person who is diagnosed can focus on taking care of their own health.

If you are the sexual partner of someone who has been diagnosed with HIV, you should also get tested so that you know your own HIV status. If you test negative, talk to your healthcare provider about <u>PrEP</u> (pre-exposure prophylaxis), taking HIV medicine daily to prevent HIV infection. PrEP is recommended for people at high risk of HIV infection, including those who are in a long-term relationship with a partner who has HIV. If you test positive, get connected to HIV treatment and care as soon as possible.

#### What If a Friend Tells You That They Have HIV?

More than a million people in the United States are living with HIV, so you may know someone who has the virus. If your friend, family member, or co-worker has been HIV-positive for some time and has just told you, here's how you can be supportive:

- **Acknowledge.** If someone has disclosed their HIV status to you, thank them for trusting you with their private health information.
- **Ask.** If appropriate, ask if there's anything that you can do to help them. One reason they may have chosen to disclose their status to you is that they need an ally or advocate, or they may need help with a particular issue or challenge. Some people are public with this information; other people keep it very private. Ask whether other people know this information, and how private they are about their HIV status.
- **Reassure.** Let the person know, through your words or actions, that their HIV status does not change your relationship and that you will keep this information private if they want you to.

• Learn. Educate yourself about HIV. Today, lots of people living with HIV are on ART and have the virus under control. Others are at different stages of treatment and care. Don't make assumptions and look to your friend for guidance.

#### 2. Getting Involved

#### How Can I Help End HIV?

Want to get involved in HIV-related efforts? Here are some ideas:

**Reach out to a local HIV service organization.** Many HIV service organizations have opportunities for people living with HIV and others to share their time and talents. Depending on the organization, volunteer opportunities may include:

- Assisting with onsite or mobile testing events by being a greeter, registrar, health educator, or HIV tester
- Providing administrative support, such as filing, data entry, or answering phones
- Helping out with special events
- Participating in fundraising or advocacy activities
- Providing language skills
- Offering professional services, such as legal assistance or medical care, if licensed

To find a local HIV service organization near you, use HIV.gov's <u>HIV Testing Sites & Care Services</u> <u>Locator</u>

**Engage with others.** <u>Social media tools</u> like Facebook, Twitter, Instagram and Snapchat offer many opportunities to connect with others who are interested and involved in HIV issues. You can also share information about HIV via these channels to help others learn more.

**Get involved in HIV awareness days.** Check out our <u>HIV awareness days page</u> to see how you can support national observances to raise awareness and encourage people to get tested for HIV, seek, or return to care. **Learn.** Stay abreast of changes in HIV prevention, care, treatment and research and learn about new tools or resources. Check out our <u>learning opportunities page</u> to find webinars, conferences, Twitter chats, and other events.

**Share what you know.** You can make a difference by learning more about HIV and sharing that knowledge with others. Talk to others about testing, how to prevent HIV, the effectiveness of treatment, and the importance of getting and staying in medical care. Use our <u>Basics pages</u> to find answers to questions you or others may have. You can easily share those pages on social media or via email using the buttons at the top right side of each page.

#### 3. Standing Up To Stigma

#### How Can You Stand Up to HIV-Related Stigma?

HIV-related stigma and discrimination still persist in the United States and negatively affect the health and well-being of people living with HIV. You can play an important role in reducing stigma and discrimination by offering your support to people living with HIV and speaking out to correct myths and stereotypes that you hear from others in your community.

- Need inspiration? View the personal stories of people who are living healthy with HIV. Visit *Positive Spin*.
- Want to learn more? CDC's *Let's Stop HIV Together* campaign raises awareness about HIV and its impact on the lives of all Americans and fights stigma by showing that persons with HIV are real people—mothers, fathers, friends, brothers, sisters, sons, daughters, partners, wives, husbands, and co-workers.

Almost 8 in 10 HIV patients in the United States report feeling **internalized HIVrelated stigma**, according to a CDC study. Internalized stigma is when a person living with HIV experiences negative feelings or thoughts about their HIV status. <u>Read</u> <u>more</u> about this and about how people living with HIV can reduce internalized stigma?

Read about <u>what federal agencies are doing</u> to confront and reduce HIV-related stigma.

#### **Chapter III. HIV Prevention**

#### A. Using HIV Medication to Reduce Risk

#### 1. HIV Treatment as Prevention

#### **HIV Treatment as Prevention**

**Treatment as prevention** (TasP) refers to taking HIV medication to prevent the sexual transmission of HIV. It is one of the highly effective options for preventing HIV transmission. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIV-negative partners.

TasP works when a person living with HIV takes HIV medication exactly as prescribed and has regular follow-up care, including regular viral load tests to ensure their viral load stays undetectable.

#### Taking HIV Medication to Stay Healthy and Prevent Transmission

If you have HIV, it is important to start treatment with HIV medication (called antiretroviral therapy or ART) as soon as possible after your diagnosis.

**If ta**ken every day, exactly as prescribed, HIV medication can reduce the amount of HIV in your blood (also called the viral load) to a very low level. This is called **viral suppression**. It is called viral suppression because HIV medication prevents the virus from growing in your body and keeps the virus very low or "suppressed." Viral suppression helps keep you healthy and prevents illness.

**Fyo**ur viral load is so low that it doesn't show up in a standard lab test, this is called having an **undetectable viral load**. People living with HIV can get and keep an undetectable viral load by taking HIV medication every day, exactly as prescribed. Almost everyone who takes HIV medication daily as prescribed can achieve an undetectable viral load, usually within 6 months after starting treatment.

There are important **health benefits** to getting the viral load as low as possible. People living with HIV who know their status, take HIV medication daily as prescribed, and get and keep an undetectable viral load can live long, healthy lives.

There is also a major **prevention benefit**. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIV-negative partners.

<u>Learn more: Read our fact sheet about the health and prevention benefits of viral</u> <u>suppression and maintaining an undetectable viral load</u> (PDF 166 KB).

#### Keep Taking Your HIV Medication to Stay Undetectable

HIV is still in your body when your viral load is suppressed, even when it is undetectable. So, you need to keep taking your HIV medication daily as prescribed. When your viral load stays undetectable, you have effectively no risk of transmitting HIV to an HIV-negative partner through sex. If you stop taking HIV medication, your viral load will quickly go back up.

If you have stopped taking your HIV medication or are having trouble taking all the doses as prescribed, talk to your health care provider as soon as possible. Your provider can help you get back on track and discuss the best strategies to prevent transmitting HIV through sex while you get your viral load undetectable again.

#### How Do We Know Treatment as Prevention Works?

Large research studies with newer HIV medications have shown that treatment *is* prevention. These studies monitored thousands of male-female and male-male couples in which one partner has HIV and the other does not over several years. No HIV transmissions were observed when the HIV-positive partner was virally suppressed. This means that if you keep your viral load undetectable, there is effectively no risk of transmitting HIV to someone you have vaginal, anal, or oral sex with. <u>Read about the scientific evidence</u>.

#### Talk with Your HIV Health Care Provider

Talk with your health care provider about the benefits of HIV treatment and which HIV medication is right for you. Discuss how frequently you should get your viral load tested to make sure it remains undetectable.

If your lab results show that the virus is detectable or if you are having trouble taking every dose of your medication, you can still protect your HIV-negative partner by using other methods of preventing sexual transmission of HIV such as condoms, safer sex practices, and/or <u>pre-exposure prophylaxis</u> (PrEP) for an HIV-negative partner until your viral load is undetectable again. Taking HIV medicine to maintain an undetectable viral load does not protect you or your partner from getting other sexually transmitted diseases (STDs), so talk to your provider about ways to <u>prevent other STDs</u>.

### Talk to Your Partner

TasP can be used alone or in conjunction with <u>other prevention strategies</u>. Talk about your HIV status with your sexual partners and decide together which prevention methods you will use. Some states have <u>laws</u> that require you to tell your sexual partner that you have HIV in certain circumstances.

### **Other Prevention Benefits of HIV Treatment**

In addition to preventing sexual transmission of HIV there are other benefits of taking HIV medication to achieve and maintain an undetectable viral load:

- It reduces the risk of mother-to-child transmission from pregnancy, labor, and delivery. If a woman living with HIV can take HIV medication as prescribed throughout pregnancy, labor, and delivery and if HIV medication is given to her baby for 4-6 weeks after delivery, the risk of transmission from pregnancy, labor, and delivery can be reduced to 1% or less. Scientists don't know if a woman living with HIV who has her HIV under control can transmit HIV to her baby through breastfeeding. While it isn't known if or how much being undetectable or virally suppressed prevents some ways that HIV is transmitted, it is reasonable to assume that it provides some risk reduction.
- *It may reduce HIV transmission risk for people who inject drugs*. Scientists do not yet know whether having a suppressed or undetectable viral load prevents HIV transmission through sharing needles or other injection drug equipment, but it is reasonable to assume that it provides some risk reduction. Even if you are taking HIV medication and are undetectable, use new equipment each time you inject and do not share needles and syringes with other people.

## 2. Pre-exposure Prophylaxis (PrEP)

On October 3<sup>rd</sup>, 2019, the U.S. Food and Drug Administration (FDA) approved a second drug for pre-exposure prophylaxis (PrEP) as part of ongoing efforts to end the HIV epidemic. The content of this page (<u>https://www.hiv.gov/hiv-basics/hiv-prevention/using-hiv-medication-to-reduce-risk/pre-exposure-prophylaxis</u>) is being revised.

What is PrEP?

PrEP, or pre-exposure prophylaxis, is an HIV prevention method in which people who don't have HIV take HIV medicine daily to reduce their risk of getting HIV if they are exposed to the virus. Currently, the only FDA-approved medication for PrEP is a combination of two anti-HIV drugs, emtricitabine and tenofovir disoproxil fumarate, sold in a single pill under the brand name Truvada<sup>™</sup>.

PrEP can stop HIV from taking hold and spreading throughout your body.

It is prescribed to HIV-negative adults and adolescents who are at high risk for getting HIV through sex or injection drug use.

### Why Take PrEP?

PrEP is highly effective when taken as indicated.

The once-daily pill reduces the risk of getting HIV from sex by more than 90%. Among people who inject drugs, it reduces the risk by more than 70%.

Your risk of getting HIV from sex can be even lower if you combine PrEP with condoms and other prevention methods.

### Is PrEP Right for You?

PrEP may benefit you if you are HIV-negative and **ANY** of the following apply to you:

You are a gay/bisexual man and you:

- have an HIV-positive partner
- have multiple partners, a partner with multiple partners, or a partner whose HIV status is unknown-and you also:
  - have anal sex without a condom, or
  - recently had a sexually transmitted infection (STI)

You are a heterosexual and you:

- have an HIV-positive partner
- have multiple partners, a partner with multiple partners, or a partner whose HIV status is unknown-and you also:
  - o don't always use a condom for sex with people who inject drugs, or
  - o don't always use a condom for sex with bisexual men



You inject drugs and you:

- share needles or equipment to inject drugs
- are at risk for getting HIV from sex

### Is PrEP Safe?

No significant health effects have been seen in people who are HIV-negative and have taken PrEP for up to 5 years.

Some people taking PrEP may have side effects, like nausea, but these side effects are usually not serious and go away over time. If you are taking PrEP, tell your health care provider if you have any side effect that bothers you or that does not go away.

And be aware: PrEP protects you against HIV but not against other sexually transmitted infections (STIs) or other types of infections. Combining PrEP with condoms will reduce your risk of getting other STIs.

### How Do You Get PrEP?



If you think PrEP may be right for you, visit your doctor or health care provider. PrEP is only available by prescription.

Because PrEP is for people who are HIV-negative, you'll have to get an HIV test before starting PrEP and you may need to get other tests to make sure it's safe for you to use PrEP.

If you take PrEP, you'll need to see your provider every 3 months for repeat HIV tests, prescription refills, and follow-up.

Many health insurance plans cover the cost of PrEP. A <u>commercial medication</u> <u>assistance program</u> is available for people who may need help paying for PrEP.

### Learn More About PrEP

If you think PrEP might be right for you, or you want to learn more visit CDC's <u>PrEP</u> <u>Basics</u>.

# 3. Post-Exposure Prophylaxis

#### What Is PEP?

PEP, or post-exposure prophylaxis, is a short course of HIV medicines taken very soon after a possible exposure to HIV to prevent the virus from taking hold in your body.

You must start it within 72 hours after you were exposed to HIV, or it won't work. Every hour counts.

PEP should be used only in emergency situations. It is not meant for regular use by people who may be exposed to HIV frequently.

#### How Do I Know If I Need PEP?

If you are HIV-negative and you think you may have been recently exposed to HIV, contact your health care provider immediately or go to an emergency room right away.

You may be prescribed PEP if you are HIV-negative or don't know your HIV status, and in the last 72 hours you:

On 5/5/18, the U.S. Food and Drug Administration (FDA) <u>alerted the public</u> that serious cases of neural tube birth defects have been reported in babies born to women with HIV who were treated with the drug dolutegravir prior to conception. The CDC has issued an <u>interim</u> <u>statement</u> on the implications for PEP. Talk to your health care professional.

- Think you may have been exposed to HIV during sex (for example, you had a condom break)
- Shared needles or works to prepare drugs
- Were sexually assaulted

Your health care provider or emergency room doctor will evaluate you and help you decide whether PEP is right for you.

In addition, if you are a health care worker, you may be prescribed PEP after a possible <u>exposure to HIV at work</u>, such as from a needlestick injury.

### **How Long Do I Need to Take PEP?**

If you are prescribed PEP, you will need to take the HIV medicines every day for 28 days.

You will also need to return to your health care provider at certain times while taking PEP and after you finish taking it for HIV testing and other tests.

### How Well Does PEP Work?

PEP is effective in preventing HIV infection when it's taken correctly, but it's not 100% effective. The sooner you start PEP after a possible HIV exposure, the better.

While taking PEP, it's important to keep using <u>other HIV prevention methods</u>, such as using condoms the right way every time you have sex and using only new, sterile needles and works when injecting drugs.

### **Does PEP Cause Side Effects?**

The HIV medicines used for PEP may cause side effects in some people. These side effects can be treated and aren't life-threatening.

If you are taking PEP, talk to your health care provider if you have any side effect that bothers you or that does not go away.

PEP medicines may also interact with other medicines that a person is taking (called a <u>drug interaction</u>). For this reason, it's important to tell your health care provider about any other medicines that you take.

### Can I Take PEP Every Time I Have Unprotected Sex?

No. PEP should be used only in emergency situations. It is not intended to replace regular use of <u>other HIV prevention methods</u>. If you feel that you might be exposed to HIV frequently, talk to your health care professional about <u>PrEP</u>.

#### How Can I Pay for PEP?

- If you're prescribed PEP after a sexual assault—You may qualify for partial or total reimbursement for medicines and clinical care costs through the Office for Victims of Crime, funded by the U.S. Department of Justice (see the <u>contact</u> <u>information for each state</u>).
- If you're prescribed PEP for another reason and you cannot get insurance coverage (Medicaid, Medicare, private, or employer-based)—Your health care provider can apply for free PEP medicines through the medication assistance programs run by drug manufacturers. These can be handled urgently in many cases to avoid a delay in getting medicine.
- If you're a health care worker who was exposed to HIV on the job—Your workplace health insurance or workers' compensation will usually pay for PEP.

Content Source: <u>HIV.gov</u> Date last updated: June 26, 2019

## **Chapter III. HIV Prevention**

### **B. Reducing Sexual Risk 1. Preventing Sexual Transmission of HIV**

There are several ways to prevent getting or transmitting HIV through sex.

**If you are HIV negative**, you can use HIV prevention medications known as preexposure prophylaxis (PrEP) or post-exposure prophylaxis (PEP) to protect yourself. You can also use other HIV prevention methods, below. **If you are living with HIV**, the most important thing you can do to prevent transmission and stay healthy is to take your HIV medication (known as antiretroviral therapy or ART), every day, exactly as prescribed. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIV-negative partners. There also are other options to choose from, below.

### How Can You Prevent Getting HIV from Anal or Vaginal Sex?

If you are HIV-negative, you have several options for protecting yourself from HIV. The more of these actions you take, the safer you can be.

### You can:

- **Use condoms.** Condoms are highly effective at preventing HIV infection if you use them the right way every time you have sex. Learn the right way to use a male condom and a female condom.
- **Reduce your number of sexual partners.** This can lower your chances of having a partner who could transmit HIV to you. The more partners you have, the more likely you are to have a partner with HIV whose viral load is not suppressed or to have a sex partner with a sexually transmitted disease. Both of these factors can increase the risk of HIV transmission.
- **Talk to your doctor about PrEP.** Pre-exposure prophylaxis (PrEP) is daily medication that can reduce your chance of getting HIV. Taken every day, PrEP can stop HIV from taking hold and spreading throughout your body. PrEP might benefit you if you are HIV-negative and have an ongoing relationship with an HIV-positive partner PrEP also should be considered if you aren't in a mutually monogamous relationship with a partner who recently tested HIV-negative, *and* you are a:
  - gay or bisexual man who has had anal sex without a condom or been diagnosed with an STD in the past 6 months;
  - man who has sex with both men and women; or
  - heterosexual man or woman who does not regularly use condoms during sex with partners of unknown HIV status who are at very high risk of HIV infection (for example, people who inject drugs or women who have bisexual male partners).
- **Take PEP within 72 hours after a possible HIV exposure**. Post-exposure prophylaxis (PEP) means taking HIV medication after being potentially exposed to HIV to prevent becoming infected. If you're HIV-negative or don't know your

HIV status and think you have recently been exposed to HIV during sex (for example, if the condom breaks), talk to your health care provider or an emergency room doctor about PEP right away (within 3 days). The sooner you start PEP, the better; every hour counts. If you're prescribed PEP, you'll need to take it once or twice daily for 28 days. Keep in mind that your chance of getting HIV is lower if your HIV-positive partner is taking HIV medication daily prescribed and his or her viral load is undetectable.

- Get tested and treated for other STDs and encourage your partners to do the same. If you are sexually active, get tested at least once a year. Having other STDs increases your risk for getting or transmitting HIV. STDs can also have long-term health consequences. Find an STD testing site.
- If you're HIV-negative and your partner is HIV-positive, encourage your partner to get and stay on HIV treatment. If taken daily as prescribed, HIV medication (ART) reduces the amount of HIV in the blood (the viral load) to a very low levels—so low that a standard lab test can't detect it. This is called having an *undetectable viral load*. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load can stay healthy and have effectively no risk of sexually transmitting HIV to an HIV-negative partner through sex.
- **Choose less risky sexual behaviors.** HIV is mainly spread by having anal or vaginal sex without a condom or without taking medicines to prevent or treat HIV. Here is some information about the risk associated with specific sexual behaviors. See CDC's HIV Risk Reduction Tool (BETA) for more information.
  - Receptive anal sex is the riskiest type of sex for getting HIV. It's possible for either partner—the partner inserting the penis in the anus (the top) or the partner receiving the penis (the bottom)—to get HIV, but it is much riskier for an HIV-negative partner to be the receptive partner. That's because the lining of the rectum is thin and may allow HIV to enter the body during anal sex.
  - Vaginal sex also carries a risk for getting HIV, though it is less risky than receptive anal sex. Most women who get HIV get it from vaginal sex, but men can also get HIV from vaginal sex.
  - In general, there is little to no risk of getting or transmitting HIV from oral sex. Theoretically, transmission of HIV is possible if an HIV-positive man ejaculates in his partner's mouth during oral sex. However, the risk is still very low, and much lower than with anal or vaginal sex. Factors that may increase the risk of transmitting HIV through oral sex are oral ulcers, bleeding gums, genital sores, and the presence of other STDs, which may

or may not be visible. For more information, see CDC's HIV Basics: How can I prevent getting HIV from oral sex?

• Sexual activities that don't involve contact with body fluids (semen, vaginal fluid, or blood) carry no risk of HIV transmission but may pose a risk for other STDs.

#### Is Abstinence an Effective Way to Prevent HIV?

Yes. Abstinence means not having oral, vaginal, or anal sex. An abstinent person is someone who's never had sex or someone who's had sex but has decided not to continue having sex for some period of time. Abstinence is the only 100% effective way to prevent HIV, other sexually transmitted diseases (STDs), and pregnancy. The longer you wait to start having oral, vaginal, or anal sex, the fewer sexual partners you are likely to have in your lifetime. Having fewer partners lowers your chances of having sex with someone who has HIV or another STD.

### If You Are Living with HIV, How Can You Prevent Passing It to Others?

If you are living with HIV, there are many actions you can take to prevent transmitting HIV to an HIV-negative partner. The more of these actions you take, the safer you can be.

- **Take HIV medication.** The most important thing you can do is to take medication to treat HIV infection (called antiretroviral therapy, or ART) every day, exactly as prescribed. Taking HIV medication daily as prescribed can make the amount of HIV in your blood (your viral load) very low—so low that a standard lab test can't detect it. This is called having an *undetectable viral load*. Getting and keeping an undetectable viral load is the best thing you can do to stay healthy. If your viral load stays undetectable, you have effectively no risk of transmitting HIV to an HIV-negative partner through sex. Learn more about HIV treatment as prevention.
- If you're taking HIV medication, follow your health care provider's advice. Visit your health care provider regularly and always take your medication as prescribed.
- Use condoms the right way every time you have sex. Learn the right way to use a male condom and a female condom.
- **Choose less risky sexual behaviors.** Anal sex is the highest-risk sexual activity for HIV transmission. If your partner is HIV-negative, it's less risky if they're the insertive partner (top) and you're the receptive partner (bottom) during anal sex. Oral sex is much less risky than anal or vaginal sex. Sexual activities that

don't involve contact with body fluids (semen, vaginal fluid, or blood) carry no risk of HIV transmission.

- If you inject drugs, never share your needles or works with anyone.
- **Talk to your HIV-negative partners about PrEP.** Pre-exposure prophylaxis (PrEP) is daily medication that can reduce an HIV-negative person's chance of getting HIV. Taken every day, PrEP can stop HIV from taking hold and spreading throughout throughout the person's body.
- **Talk to your HIV-negative partners about post-exposure prophylaxis** (PEP) if you think they've recently had a possible exposure to HIV (for example, if they had anal or vaginal sex without a condom or if the condom broke during sex). Your partners should talk to a health care provider right away (within 72 hours) after a possible exposure. Starting PEP immediately and taking it daily for 28 days will reduce their chance of getting HIV.
- Get tested and treated for other STDs and encourage your partners to do the same. If you are sexually active, get tested at least once a year. STDs can have long-term health consequences. They can also increase the risk of getting or transmitting HIV. Find an STD testing site.

Also, encourage your partners who are HIV-negative to get tested for HIV so they are sure about their status and can take action to keep themselves healthy. Use HIV.gov's HIV Testing Sites & Care Services Locator to find a testing site nearby.

Content Source: HIV.gov Date last updated: October 12, 2018

## **Chapter III. HIV Prevention**

### C. Reducing Risk from Alcohol and Drug Use 1. Alcohol and HIV Risk

Drinking alcohol, particularly binge drinking, affects your brain, making it hard to think clearly. When you're drunk, you may be more likely to make poor decisions that put you at risk for getting or transmitting HIV, such as having sex without a condom.

You also may be more likely to have a harder time <u>using a condom the right way</u> every time you have sex, have more sexual partners, or <u>use other drugs</u>. Those behaviors can

increase your risk of exposure to HIV and other sexually transmitted diseases. Or, if you have HIV, they can also increase your risk of transmitting HIV to others.

### What Can You Do?

If you drink alcohol:

- Drink in moderation. <u>Moderate drinking</u> is up to 1 drink per day for women and up to 2 drinks per day for men. One drink is a 12-ounce bottle of beer, a 5-ounce glass of wine, or a shot of liquor.
- Visit <u>Rethinking Drinking</u>, a website from NIH's National Institute on Alcohol Abuse and Alcoholism (NIAAA). This website can help you evaluate your drinking habits and consider how alcohol may be affecting your health.
- Don't have sex if you're drunk or high from other drugs.
- Use a condom every time you have sex. Read this fact sheet from the Centers for Disease Control and Prevention (CDC) on <u>how to use condoms correctly</u>. You can also consider <u>sexual activities that are lower risk for HIV</u> than anal or vaginal sex (like oral sex).
- If you are HIV-negative, talk to your health care provider about <u>PrEP</u>. PrEP is when people at very high risk for HIV take HIV medicine (called antiretroviral therapy or ART) daily to lower their chances of getting HIV. PrEP must be taken every day as prescribed and alcohol use can make it hard to stick to a daily HIV regimen. Be open and honest about your alcohol use so you and your doctor can develop a plan for you to stick to your HIV medicine.
- If you are living with HIV, <u>taking ART every day</u>, <u>exactly as prescribed</u> is also important to stay healthy and prevent transmission. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIV-negative partners. Like PrEP, ART must be taken every day, exactly as prescribed.

### Need help?

- Therapy and other methods are available to help you stop or cut down on your alcohol use if you have a problem. Talk with a counselor, doctor, or other health care provider about options that might be right for you.
- To find a treatment center near you, <u>use the SAMHSA Behavioral Health</u> <u>Treatment Locator</u> or call 1-800-662-HELP (4357). Open 24/7.

### **Staying Healthy**

If you are living with HIV, alcohol use can be harmful to your brain and body and affect your ability to stick to your HIV treatment. Learn about the <u>health effects of alcohol</u> <u>and other drug use</u> and how to access alcohol treatment programs if you need them.

Content Source: <u>HIV.gov</u> Date last updated: August 27, 2018

### 2. Substance Use and HIV Risk

### How Can Using Drugs Put Me at Risk for Getting or Transmitting HIV?

<u>Using drugs</u> affects your brain, alters your judgment, and lowers your inhibitions. When you're high, you may be more likely to make poor decisions that put you at risk for getting or transmitting HIV, such as having sex without a condom, have a hard time <u>using a condom the right way</u> every time you have sex, have more sexual partners, or use other drugs. These behaviors can increase your risk of exposure to HIV and other sexually transmitted diseases. Or, if you have HIV, they can increase your risk of spreading HIV to others.

And if you inject drugs, you are at risk for getting or transmitting HIV and hepatitis B and C if you share needles or equipment (or "works") used to prepare drugs, like cotton, cookers, and water. This is because the needles or works may have blood in them, and blood can carry HIV. You should not share needles or works for injecting silicone, hormones, or steroids for the same reason.

Here are some commonly used substances and their link to HIV risk:

- 1. **Alcohol.** Excessive alcohol consumption, notably binge drinking, can be an important risk factor for HIV because it is linked to risky sexual behaviors and, among people living with HIV, can hurt treatment outcomes.
- 2. **Opioids.** <u>Opioids</u>, a class of drugs that reduce pain, include both prescription drugs and heroin. They are associated with HIV risk behaviors such as needle sharing when infected and risky sexual behaviors, and have been linked to outbreaks of HIV and viral hepatitis. People who are addicted to opioids are also at risk of turning to other ways to get the drug, including trading sex for drugs or money, which increases HIV risk.
- 3. **Methamphetamine.** "Meth" is linked to risky sexual behaviors, such as having more sexual partners or sex without a condom, that place people at greater risk

for HIV and other sexually transmitted diseases. Meth acn be injected, which also increases HIV risk if people share needles and other injection equipment.

- 4. **Crack cocaine.** Crack cocaine is a stimulant that can create a cycle in which people quickly exhaust their resources and may engage in behaviors to obtain the drug that increase their HV risk.
- 5. **Inhalants.** Use of amyl nitrite ("poppers") has long been linked to risky sexual behaviors, illegal drug use, and sexually transmitted diseases among gay and bisexual men.

Therapy, medicines, and other methods are available to help you stop or cut down on drinking or using drugs. Talk with a counselor, doctor, or other health care provider about options that might be right for you. To find a substance abuse treatment center near you, visit <u>SAMHSA's treatment locator</u> or call 1-800-662-HELP (4357).

# How Can You Prevent Getting or Transmitting HIV from Injection Drug Use?

Your risk is high for getting or transmitting HIV and hepatitis B and C if you share needles or equipment (or "works") used to prepare drugs, like cotton, cookers, and water. This is because the needles or works may have blood in them, and blood can carry HIV.

If you inject drugs, you are also at risk of getting HIV (and other sexually transmitted diseases) because you may be more likely to take risks with sex when you are high.

The best way to lower your chances of getting HIV is to stop injecting drugs. You may need help to stop or cut down using drugs, but there are many resources available to help you. To find a substance abuse treatment center near you, visit <u>SAMHSA's</u> <u>treatment locator</u> or call 1-800-662-HELP (4357).

If you keep injecting drugs, here are some ways to lower your risk for getting HIV and other infections:

- Use only new, sterile needles and works each time you inject. Many communities have needle exchange programs where you can get new needles and works, and some pharmacies may sell needles without a prescription.
- Never share needles or works.
- Clean used needles with bleach only when you can't get new ones. Bleaching a needle may reduce the risk of HIV but doesn't eliminate it.
- Use sterile water to fix drugs.

- Clean your skin with a new alcohol swab before you inject.
- Be careful not to get someone else's blood on your hands or your needle or works.
- Dispose of needles safely after one use. Use a sharps container, or keep used needles away from other people.
- Get tested for HIV at least once a year
- Ask your doctor about taking daily medicine to prevent HIV called <u>pre-exposure</u> <u>prophylaxis</u> (PrEP).
- If you think you've been exposed to HIV within the last 3 days, ask a health care provider about <u>post-exposure prophylaxis</u> (PEP) right away. PEP can prevent HIV, but it must be started within 72 hours.
- Don't have sex if you're high. If you do have sex, make sure to protect yourself and your partner by <u>using a condom the right way</u> every time or by using other effective methods.







### What Are Syringe Services Programs?

Many communities have <u>syringe services programs</u>, also called syringe exchange programs or needle exchange programs. SSPs are places where injection drug users can get new needles and works, along with other services such as help with stopping substance abuse; testing and, if needed, linkage to treatment for HIV, hepatitis B, and hepatitis C; and education on what to do for an overdose. SSPs have been demonstrated to be an effective component of a comprehensive approach to prevent HIV and viral hepatitis among people who inject drugs, while not increasing illegal drug use.<u>Find one near you.</u>

### **Staying Healthy**

If you are living with HIV, substance use can be harmful to your brain and body and affect your ability to stick to your HIV treatment regimen. Learn about the <u>health</u> <u>effects of alcohol and other substance use</u> and how to access substance abuse treatment programs if you need them.

Content Source: <u>HIV.gov</u> Date last updated: August 27, 2018

## **Chapter III. HIV Prevention**

### D. Reducing Mother-to-Child Risk 1. Preventing Mother-to-Child Transmission of HIV

An HIV-positive mother can transmit HIV to her baby in during pregnancy, childbirth (also called labor and delivery), or breastfeeding.

If you are a woman living with HIV and you are pregnant, treatment with a combination of HIV medicines (called antiretroviral therapy or ART) can prevent transmission of HIV to your baby and protect your health.

### How Can You Prevent Giving HIV to Your Baby?

Women who are pregnant or are planning a pregnancy should get tested for HIV as early as possible. If you have HIV, the most important thing you can do is to take ART every day, exactly as prescribed.

If you're pregnant, talk to your health care provider about getting tested for HIV and how to keep you and your child from getting HIV. Women in their third trimester should be tested again if they engage in behaviors that put them at risk for HIV.

If you are HIV-negative and you have an HIV-positive partner, talk to your doctor about taking pre-exposure prophylaxis (PrEP) to help keep you from getting HIV. Encourage your partner to take ART. People with HIV who take HIV medicine as prescribed and get and keep an undetectable viral load have effectively no risk of transmitting HIV to an HIV-negative partner through sex.

If you have HIV, take ART daily as prescribed. If your viral load is not suppressed, your doctor may talk with you about options for delivering the baby that can reduce transmission risk. After birth, babies born to a mother with HIV are given ART right away for 4 to 6 weeks. If you are treated for HIV early in your pregnancy, the risk of transmitting HIV to your baby can be 1% or less. Breast milk can have HIV in it. So, after delivery, you can prevent giving HIV to your baby by not breastfeeding.

For more information, see CDC's HIV Among Pregnant Women, Infants, and Children.

**Content Source:** CDC's HIV Basics **Date last updated:** December 19, 2018

### **Chapter III. HIV Prevention**

### E. Potential Future Options 1. HIV Vaccine

#### What Are Vaccines and What Do They Do?

A vaccine—also called a "shot" or "immunization"—is a substance that teaches your body's immune system to recognize and defend against harmful viruses or bacteria.

Vaccines given **before** you get infected are called "preventive vaccines" or "prophylactic vaccines," and you get them while you are healthy. This allows your body to set up defenses against those dangers ahead of time. That way, you won't get sick if you're exposed to diseases later. Preventive vaccines are widely used to prevent diseases like polio, chicken pox, measles, mumps, rubella, influenza (flu), hepatitis A and B, and human papillomavirus (HPV).

### Is There a Vaccine for HIV?

No. There is currently no vaccine available that will prevent HIV infection or treat those who have it.

However, scientists are working to develop one. Building on the findings of an earlier study that found for the first time, albeit modestly, that a vaccine could prevent HIV infection in 2016, an NIH-supported clinical trial was launched to test a modified HIV vaccine. This current vaccine trial, called HVTN 702, is testing whether an experimental vaccine regimen safely prevents HIV infection among South African adults. Learn more in this <u>blog post</u> and in the video below.

#### Why Do We Need an HIV Vaccine?

Today, more people living with HIV than ever before have access to lifesaving <u>treatment with HIV medicines</u> (called antiretroviral therapy or ART), which is good for their health. When people living with HIV achieve and maintain viral suppression by taking medication as prescribed, they can stay healthy for many years and greatly reduce their chance of transmitting HIV to their partners. In addition, others who are at high risk for HIV infection may have access to <u>pre-exposure</u> <u>prophylaxis</u> (PrEP), or ART being used to prevent HIV. Yet, unfortunately, in 2015, 39,513 people were diagnosed with HIV infection in the United States, and more than 2.1 million people became newly infected with HIV worldwide. To control and ultimately end HIV globally, we need a powerful array of HIV prevention tools that are widely accessible to all who would benefit from them.

Vaccines historically have been the most effective means to prevent and even eradicate infectious diseases. They safely and cost-effectively prevent illness, disability, and death. Like smallpox and polio vaccines, a preventive HIV vaccine could help save millions of lives.

#### Developing safe, effective, and affordable vaccines that can prevent HIV infection in uninfected people is the NIH's highest HIV research priority given its gamechanging potential for controlling and ultimately ending the HIV/AIDS pandemic.

The long-term goal is to develop a safe and effective vaccine that protects people worldwide from getting infected with HIV. However, even if a vaccine only protects some people who get vaccinated, or even if it provides less than total protection by reducing the risk of infection, it could still have a major impact on the rates of transmission and help control the pandemic, particularly for populations at high risk of HIV infection. A partially effective vaccine could decrease the number of people who get infected with HIV, further reducing the number of people who can pass the virus on to others. By substantially reducing the number of new infections, we can stop the epidemic.

For more information, see the video below with Dr. Anthony Fauci, Director of NIH's National Institutes of Allergy and Infectious Diseases (NIAID).

### 2. Long-acting PrEP

#### Long-Acting HIV Prevention Tools

### What Are Long-acting HIV Prevention Tools?

Long-acting HIV prevention tools are new long-lasting forms of HIV prevention being studied by researchers. These are HIV prevention tools that can be inserted, injected,

infused, or implanted in a person's body from once a month to once a year to provide sustained protection from acquiring HIV. These products are not available now, but they might be in the not-too-distant future.

### Why Are Long-acting HIV Prevention Tools Needed?

Currently, people who are HIV-negative but at very high risk for HIV can lower their chances of getting HIV by taking a pill that contains two anti-HIV drugs every day. This is called pre-exposure prophylaxis (PrEP). When taken daily, PrEP can stop HIV from taking hold and spreading throughout your body.

PrEP is highly effective when taken daily as prescribed. However, studies have shown that PrEP is much less effective if it is not taken consistently, and that taking a daily pill can be challenging for some people.

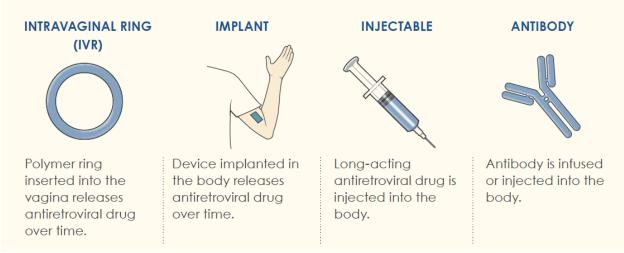
# That's why researchers are working to create **new HIV prevention tools that do not require taking a daily pill**.

Scientists funded by the National Institutes of Health (NIH) are developing and testing several long-acting forms of HIV prevention that can be inserted, injected, infused, or implanted in a person's body from once a month to once a year. The goal of this research is to provide people with a variety of acceptable, discreet, and convenient choices for highly effective HIV prevention. None of the research on these possible HIV prevention options has been completed, so they are not yet approved by the FDA and are not available for use outside of a clinical trial.

### What Types of Long-acting HIV Prevention Tools Are Under Study?

Four types of long-acting HIV prevention are in design and testing in research studies: intravaginal rings, injectable drugs, implants, and antibodies.





NIH National Institute of Allergy and Infectious Diseases: Long-Acting Forms of HIV Prevention

**Intravaginal rings for women.** Long-acting intravaginal rings are polymer-based products that are inserted into the vagina, where they release release one or more anti-HIV (or antiretroviral) drugs over time. The intravaginal ring at the most advanced stage of research is the dapivirine ring, which was tested in two large clinical trials including the NIH-funded ASPIRE study. The dapivirine ring is undergoing further evaluation in the HOPE open-label extension trial.

**Injectables.** Long-acting injectables are select long-acting antiretroviral drugs that are injected into the body. Injectables are being studied for both HIV prevention and HIV treatment. The first large-scale clinical trial of a long-acting injectable for HIV prevention began in December 2016. Called HPTN 083, the NIH-sponsored study—a partnership with ViiV Healthcare and the Bill & Melinda Gates Foundation—is examining whether a long-acting form of the investigational antiretroviral drug cabotegravir, injected once every 8 weeks, can safely protect men and transgender women from HIV infection at least as well as daily PrEP. Results are expected in 2021. A related study called HPTN 084 is testing whether injectable cabotegravir safely prevents HIV infection in young women.

**Implants.** Long-acting implants are small devices that are implanted in the body and release an anti-HIV drug at a controlled rate for continuous protection from HIV over time. NIH is funding the development and testing of several of these implants for HIV prevention. These products have not yet entered clinical trials. Studies supported by other funders are exploring an implant for women that protects users from both HIV and unplanned pregnancy.

**Antibodies.** Scientists have begun to test whether giving people periodic infusions of powerful anti-HIV antibodies can prevent or treat HIV infection. The antibodies involved can stop a wide variety of HIV strains from infecting human cells and thus are described as "broadly neutralizing antibodies" (bNAbs). Two advanced NIH-funded clinical trials are assessing whether giving infusions of bNAbs to healthy men and women at high risk for HIV protects them from acquiring the virus. Several early-stage clinical trials of other bNAbs for HIV prevention also are underway.

### **Can I Use Long-acting HIV Prevention Tools Now?**

No. At this time, some forms of long-acting HIV prevention are being tested in clinical trials. Since their effectiveness has not yet been proven, they have not been considered for approval by the FDA. So, **they are not available for your doctor to prescribe yet**. However, NIH-supported clinical trials may be seeking volunteers to participate in some studies on long-acting HIV prevention tools. You may be eligible to participate in one of these trials, which are listed in NIAID's Long-Acting Forms of HIV Prevention infographic. Information about these trials can be found at ClinicalTrials.gov or by calling (800)411-1222.

It will probably be several years before long-acting HIV prevention tools are available to the public. In the meantime, the best forms of prevention against sexual transmission of HIV continue to be:

- HIV testing—so that you know your own HIV status and your partner's too.
- Antiretroviral therapy for people who have HIV, to protect their health and prevent transmitting the virus to their sexual partners. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIVnegative partners. This is called treatment as prevention.
- Daily oral PrEP for people who do not have HIV but are at very high risk of getting it.
- Using condoms consistently and correctly. (Learn the right way to use a male condom.)
- Choosing less risky sexual behaviors. HIV is mainly spread by having anal or vaginal sex without a condom or without taking medicines to prevent or treat HIV.
- Reducing the number of people you have sex with.
- Post-exposure prophylaxis, or PEP, meaning taking antiretroviral medicines very soon after being potentially exposed to HIV to prevent becoming infected.

The more of these actions you take, the safer you will be. To learn more about steps you can take now to prevent getting or transmitting HIV, read other pages in HIV.gov's HIV Prevention section.

*This page was developed in collaboration with NIH's National Institute of Allergy and Infectious Diseases.* 

Content Source: HIV.gov Date last updated: July 20, 2019

### 3. Microbicides

#### What Are Microbicides?

Microbicides are experimental products containing drugs that prevent vaginal and/or rectal transmission of HIV and/or sexually transmitted infections. Researchers are studying microbicides delivered in the form of vaginal rings, gels, films, inserts and enemas. A safe, effective, desirable, and affordable microbicide against HIV could help to prevent many new infections.

### **Can Microbicides Prevent HIV Infection?**

The answer to this question now appears to be "Yes, to a modest degree."

Several large-scale research studies over the past decade have investigated the safety and effectiveness of different microbicides.

In 2016, results from the NIH-funded ASPIRE study, a large clinical trial conducted at 15 clinical research sites in Malawi, South Africa, Uganda, and Zimbabwe, showed that a vaginal ring that continuously releases the experimental antiretroviral drug dapivirine provided a modest level of protection against HIV infection in women. The ring reduced the risk of HIV infection by 27 percent in the study population overall and by 61 percent among women ages 25 years and older, who used the ring most consistently.

A second clinical trial called The Ring Study conducted in parallel with the ASPIRE study also tested the dapivirine ring for safety and efficacy in women. Similar to ASPIRE, The Ring Study investigators found an overall effectiveness of 31 percent, with a slightly greater reduction in risk of HIV infection among women older than 21 years.

To build on the findings from these studies, NIH's National Institute of Allergy and Infectious Diseases (NIAID) is funding an open-label extension study of the vaginal ring to see if this experimental product can offer increased protection against HIV in an open-label setting in which all participants are counseled on how effective the ring may be, and are invited to use or not use the dapivirine ring in order to yield insight into why some women may choose to use or not to use the ring. Finding HIV prevention options that are acceptable to women and that can be integrated into their daily lives is a critical component of developing prevention strategies that work for diverse populations.

Other studies are examining potential rectal microbicide gels to reduce the risk of HIV transmission through anal sex. Some are testing microbicides originally formulated for vaginal use to determine if they are safe, effective, and acceptable when used in the rectum; others focus on the development of products designed specifically for rectal use.

Learn more about prior microbicides studies and NIAID's ongoing research on both vaginal and rectal microbicides.

### Why Are Microbicides Important?

The only currently licensed and available biomedical HIV prevention product comes in the form of a daily pill taken orally (tenofovir-emtricitabine sold as Truvada®), and is called pre-exposure prophylaxis, or PrEP. But protection from it requires consistent, daily use. A daily pill can be challenging for some people to take, so other forms of biomedical HIV prevention are being explored. A discreet, long-acting, female-initiated method of prevention such as a microbicide may be a good HIV prevention option for some women.

Microbicides may also be preferable to condoms as an HIV prevention option for some women because women would not have to negotiate their use with a partner, as they often must do with condoms. Because women and girls are at particularly high risk for HIV in many parts of the world, it is especially important to have an effective, desirable, woman-initiated HIV prevention tool. Microbicides could make it possible for a woman to protect herself from HIV. In the future, it may be possible to formulate products that combine anti-HIV microbicide agents with contraception.

Rectal microbicides would also offer another HIV prevention option for men or women who engage in anal sex.

### Can You Use a Microbicide to Prevent HIV?

Not yet. The ASPIRE study results are promising, but further study is needed, along with approval by drug regulators before the vaginal ring can be used by the public. Meanwhile, research on other formulations and forms of microbicides continues.

For now, available forms of protection against sexual transmission of HIV continue to be:

- Antiretroviral therapy for people who have HIV, to reduce their risk of transmitting the virus to their sexual partners (i.e., treatment as prevention)
- Daily PrEP
- Voluntary medical male circumcision
- HIV testing—so that you know your own HIV status and your partner's, too.
- Using condoms consistently and correctly.
- Choosing less risky sexual behaviors.
- Reducing the number of people you have sex with.

The more of these actions you take, the safer you will be. To learn more, see Lower Your Sexual Risk for HIV.

# **Chapter IV. HIV Testing**

### A. Learn About HIV Testing 1. Who Should Get Tested?

The only way to know for sure whether you have HIV is to get tested. CDC recommends that everyone between the ages of 13 and 64 get tested for HIV at least once as part of routine health care. Knowing your HIV status gives you powerful information to help you take steps to keep you and your partner(s) healthy. **About 1 in 7 people in the United States who have HIV do not know they have it.** 

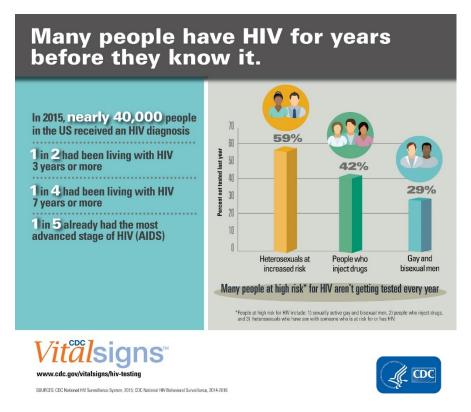
### Should You Get Tested for HIV?

Everyone between the ages of 13 and 64 should get tested for HIV at least once. If your behavior puts you at risk after you are tested, you should think about being tested again. Some people at higher risk should get tested more often.

If your last HIV test result was negative, you should get an HIV test if you answer "yes" to any of the questions below about your risk since that test:

- Are you a man who has had sex with another man?
- Have you had sex—anal or vaginal—with an HIV-positive partner?
- Have you had more than one sex partner?
- Have you injected drugs and shared needles or works (for example, water or cotton) with others?
- Have you exchanged sex for drugs or money?
- Have you been diagnosed with, or sought treatment for, another sexually transmitted disease?
- Have you been diagnosed with or treated for hepatitis or tuberculosis (TB)?
- Have you had sex with someone who could answer "yes" to any of the above questions or someone whose sexual history you don't know?

Sexually active gay and bisexual men may benefit from more frequent testing (for example, every 3 to 6 months).



If you're pregnant, talk to your health care provider about getting tested for HIV and <u>other ways to protect you and your child from getting HIV.</u>

Anyone who has been sexually assaulted or has had a high-risk exposure to HIV should consider taking <u>post-exposure prophylaxis</u> (PEP) and getting an HIV antigen test that can detect infection sooner than standard antibody testing. PEP may prevent HIV infection after possible exposure to HIV if it is started as soon as possible within 3 days after exposure to HIV.

### How Can Testing Help You?

The only way to know for sure whether you have HIV is to get tested.

Knowing your HIV status gives you powerful information to help you take steps to keep you and your partner(s) healthy.

• If you test positive, you can take medicine to treat HIV. People with HIV who take HIV medicine as prescribed can live long and healthy lives. There's also an <u>important prevention benefit</u>. If you take HIV medicine daily as prescribed and get and keep an undetectable viral load, you have effectively no risk of transmitting HIV to an HIV-negative partner through sex.

- If you test negative, you have more <u>prevention tools</u> available today to prevent HIV than ever before.
- If you are <u>pregnant</u>, you should be tested for HIV so that you can begin treatment if you're HIV-positive. If an HIV-positive woman is treated for HIV early in her pregnancy, the risk of transmitting HIV to her baby can be very low.

### Should You Get Tested for HIV If You Don't Think You're at High Risk?

Some people who test positive for HIV were not aware of their risk. That's why CDC recommends that everyone between the ages of 13 and 64 get tested for HIV at least once as part of routine health care and that people with certain risk factors should get tested more often (see above).

Even if you are in a monogamous relationship (both you and your partner are having sex only with each other), you should find out for sure whether you or your partner has HIV.

#### Should You Get Tested for HIV If You're Pregnant?

All pregnant women should be tested for HIV so that they can <u>begin treatment if</u> <u>they're HIV-positive</u>. If a woman is treated for HIV early in her pregnancy, the risk of transmitting HIV to her baby can be very low. Testing pregnant women for HIV infection, treating those who are infected, and treating their babies with <u>antiretroviral</u> <u>therapy</u> (ART) after delivery have led to a big decline in the number of children born with HIV.

The treatment is most effective for preventing HIV transmission to babies when started as early as possible during pregnancy. If pregnant women are treated for HIV early in their pregnancy, the risk of transmitting HIV to their baby can be 1% or less. However, there are still great health benefits to beginning preventive treatment even during labor or shortly after the baby is born.

# Learn more about how to protect yourself and your partners, and get information tailored to meet your needs from CDC's <u>HIV Risk Reduction Tool</u> (BETA).

Content Source: <u>CDC's HIV Basics</u> Date last updated: June 14, 2018

### 2. HIV Testing Locations

### Where Can You Get Tested for HIV?

You can get an HIV test at many places:

- Your health care provider's office
- Health clinics or community health centers
- STD or sexual health clinics
- Your local health department
- Family planning clinics
- VA medical centers
- Substance abuse prevention or treatment programs

Many pharmacies and some community-based organizations also offer HIV testing.

HIV testing is covered by health insurance without a co-pay, as required by the Affordable Care Act. If you do not have health insurance, some testing sites may offer free tests.

These places can connect you to HIV care and treatment if you test positive or can discuss the best HIV prevention options for you if you test negative.

You can also buy a home testing kit at a pharmacy or online.

### How Do I Find HIV Testing Sites Near Me?

Find an HIV test site near you by using the HIV.gov HIV services locator.



You can also find a testing site near you by:

- calling 1-800-CDC-INFO (232-4636),
- visiting gettested.cdc.gov, or
- texting your ZIP code to KNOW IT (566948).



Testing for HIV Testing is Fast, Free & Confidential

cdc.gov/DoingIt #DoingIt

Content Source: <u>HIV.gov</u> Date last updated: May 17, 2019

## 3. HIV Testing Overview

What Can You Expect When You Go in for an HIV Test?

If you take a test in a health care setting, when it's time to take the test, a health care provider will take your sample (blood or oral fluid), and you may be able to wait for the results if it's a rapid HIV test. If the test comes back negative, and you haven't had an exposure for 3 months, you can be confident you're not infected with HIV.

If your HIV test result is positive, you may need to get a follow-up test to be sure you have HIV.

Your health care provider or counselor may talk with you about your risk factors, answer questions about your general health, and discuss next steps with you, especially if your result is positive.

# How Soon After Exposure to HIV Can an HIV Test Detect If You Are Infected?

No HIV test can detect HIV immediately after infection. If you think you've been exposed to HIV, talk to your health care provider as soon as possible.

The time between when a person gets HIV and when a test can accurately detect it is called the *window period*. The window period varies from person to person and also depends upon the type of HIV test.

- Most HIV tests, including most rapid tests and home tests, are **antibody tests**. Antibodies are produced by your immune system when you're exposed to viruses like HIV or bacteria. HIV antibody tests look for these antibodies to HIV in your blood or oral fluid. It takes time for the body to produce enough antibodies for an HIV test to show that a person has HIV.
- The soonest an antibody test will detect infection is 3 weeks. Most (approximately 97%), but not all, people will develop detectable antibodies within 3 to 12 weeks (21 to 84 days) of infection. If you have any type of antibody test and have a positive result, you will need to take a follow-up test to confirm your result.
- A **combination**, **or fourth-generation**, **test** looks for both HIV antibodies and antigens. Antigens are foreign substances that cause your immune system to activate. The antigen is part of the virus itself and is present during acute HIV infection (the phase of infection right after people are infected but before they develop antibodies to HIV). Combination tests are now recommended for HIV testing that's done in labs and are becoming more common in the U.S.

- Most, but not all people, will make enough antigens and antibodies for fourthgeneration or combination tests to accurately detect infection 2 to 6 weeks (13 to 42 days) after infection.
- A **nucleic acid test** (NAT) looks for HIV in the blood. It looks for the virus and not the antibodies to the virus. This test is very expensive and not routinely used for screening individuals unless they recently had a high-risk exposure or a possible exposure with early symptoms of HIV infection.
- Most, but not all people, will have enough HIV in their blood for a nucleic acid test to detect infection 1 to 4 weeks (7 to 28 days) after infection.

Ask your health care provider about the window period for the test you're taking and whether you will need a follow-up test to confirm the results. If you're using a home test, you can get that information from the materials included in the test's package. If you get an HIV test within 3 months after a potential HIV exposure and the result is negative, get tested again in 3 more months to be sure.

If you learned you were HIV-negative the last time you were tested, you can only be sure you're still negative if you haven't had a potential HIV exposure since your last test. If you're sexually active, continue to take actions to prevent HIV, like using condoms the right way every time you have sex and taking medicines to prevent HIV if you're at high risk.



NIH/AIDSinfo: Flow Chart of Positive/Negative HIV Test Results

### Who Will Pay for Your HIV Test?

HIV screening is covered by health insurance without a co-pay, as required by the Affordable Care Act. If you do not have medical insurance, some testing sites may offer

free tests. See <u>Where to Get Tested</u> for information about locating a testing site near you.

**Content Source:** <u>Division of HIV/AIDS Prevention</u>, and <u>National Center for HIV/AIDS, Viral</u> <u>Hepatitis, Sexual Transmitted Diseases and Tuberculosis Prevention</u>, and <u>Centers for Disease</u> <u>Control and Prevention</u>

Date last updated: May 14, 2018

### 4. Understanding HIV Test Results

HIV testing shows whether a person is infected with HIV. HIV stands for human immunodeficiency virus. HIV is the virus that causes AIDS (acquired immunodeficiency syndrome). AIDS is the most advanced stage of HIV infection. Learn about what a positive and negative HIV test result mean.

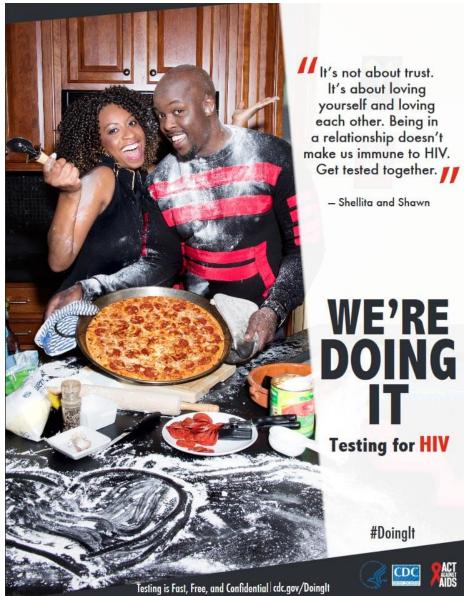
### What Does a Negative HIV Test Result Mean?

A negative result doesn't necessarily mean that you don't have HIV. That's because of the window period—the time between when a person gets HIV and when a test can accurately detect it. The window period varies from person to person and is also different depending upon the type of HIV test.

Ask your health care provider about the window period for the kind of test you're taking. If you're using a home test, you can get that information from the materials included in the test's package. If you get an HIV test after a potential HIV exposure and the result is negative, **get tested again after the window period** for the test you're using to be sure. To learn more about the window period and when a person should get retested, see CDC's How soon after an exposure to HIV can an HIV test if I am infected?. If you get an HIV test within 3 months after a potential HIV exposure and the result is negative, get tested again in 3 more months to be sure.

If you learned you were HIV-negative the last time you were tested, you can only be sure you're still negative if you haven't had a potential HIV exposure since your last test. If you're sexually active, continue to take actions to prevent HIV, like using condoms the right way every time you have sex and taking medicines to prevent HIV if you're at high risk.

# If You Have a Negative Test Result, Does that Mean that Your Partner Is HIV-Negative Also?



No. Your HIV test result reveals only your HIV status.

HIV is not necessarily transmitted every time you have sex. Therefore, taking an HIV test is not a way to find out if your partner is infected.

It's important to be open with your partner(s) and ask them to tell you their HIV status. But keep in mind that your partner(s) may not know or may be wrong about their status, and some may not tell you if they have HIV even if they know they're infected. Consider getting tested together so you can both know your HIV status and take steps to keep yourselves healthy.

### What Does a Positive HIV Test Result Mean?

If you have a positive HIV test result, a follow-up test will be conducted. If the followup test is also positive, it means you are HIV-positive.

If you had a rapid screening test, the testing site will arrange a follow-up test to make sure the screening test result was correct. If you used a self-testing kit at home, a positive HIV test result must always be confirmed by additional HIV testing performed in a health care setting. If your blood was tested in a lab, the lab will conduct a followup test on the same sample.

If your follow-up test result confirms you are infected with HIV, the next thing is to take steps to protect your health and prevent transmission to others. Begin by talking to your health care provider about antiretroviral therapy (ART). ART is the use of HIV medicines to treat HIV infection. People on ART take a combination of HIV medicines every day. ART can keep you healthy for many years and greatly reduces your chance of transmitting HIV to your sex partner(s) if taken the right way, every day. Your health care provider will help you decide what HIV medicines to take.

If you have health insurance, your insurer is required to cover some medicines used to treat HIV. If you don't have health insurance, or you need help because your insurance doesn't pay for the treatment you need, there are Federal resources that may help you.

To lower your risk of transmitting HIV,

- Take medicines to treat HIV (antiretroviral therapy or ART) the right way every day so that you achieve and maintain an undectable viral load.
- Use condoms the right way every time you have sex. Learn the right ways to use a male condom and a female condom.
- If your partner is HIV-negative, encourage them to talk to their health care provider to see if taking daily medicine to prevent HIV (called pre-exposure prophylaxis, or PrEP) is right for them.
- If you think your partner might have been recently exposed to HIV—for example, if the condom breaks during sex and you are not virally suppressed they should talk to a health care provider right away (no later than 3 days) about taking medicines (called post-exposure prophylaxis, or PEP) to prevent getting HIV.
- Get tested and treated for STDs and encourage your partner to do the same.

Receiving a diagnosis of HIV can be a life-changing event. People can feel many emotions—sadness, hopelessness, and even anger. Allied health care providers and

social service providers, often available at your health care provider's office, will have the tools to help you work through the early stages of your diagnosis and begin to manage your HIV.

Talking to others who have HIV may also be helpful. Find a local HIV support group. Learn about how other people living with HIV have handled their diagnosis.

You can view stories and testimonials of how people are staying adherent to their HIV treatment and living well with HIV by visiting HIV.gov's *Positive Spin*.

### If You Test Positive for HIV, Does That Mean You Have AIDS?

No. Testing positive for HIV does not mean you have AIDS. AIDS is the most advanced stage of HIV disease. HIV can lead to AIDS if not treated.

See What Are HIV and AIDS for more information.

#### Will Other People Know Your Test Result?

If you take an anonymous test, no one but you will know the result. If you take a confidential test, your test result will be part of your medical record, but it is still protected by state and federal privacy laws. Most testing is done confidentially.

- **Anonymous testing** means that nothing ties your test results to you. When you take an anonymous HIV test, you get a unique identifier that allows you to get your test results. These tests are not available at every place that provides HIV testing.
- **Confidential testing** means that your name and other identifying information will be attached to your test results. The results will go in your medical record and may be shared with your health care providers and your health insurance company. Otherwise, the results are protected by state and federal privacy laws, and they can be released only with your permission.

With confidential testing, if you test positive for HIV, the test result and your name will be reported to the state or local health department to help public health officials get better estimates of the rates of HIV in the state. The state health department will then **remove all personal information** about you (name, address, etc.) and share the remaining non-identifying information with CDC. CDC does not share this information with anyone else, including insurance companies. As a follow up to a positive HIV test, the local health department may contact you to make sure that you received the test results and understood them, and to find out whether you received referrals to HIV medical care and social services and whether you have received HIV medical care and treatment. The health department representative may talk with you about the need to tell your sexual or needle-sharing partner(s) about their possible exposure to HIV. They may also offer partner services to assist you with these conversations. If you want, the health department can try attempt to locate any or all of your partners to let them know they may have been exposed to HIV. They will be able to help them find a place to get tested and give them information about PrEP, PEP, and other ways that they can protect themselves and access other prevention and care services.

If you are HIV-positive, it is important to disclose your HIV status to your health care providers (doctors, dentists, etc.) so that they can give you the best possible care. You may also consider disclosing your status to others.

Content Source: CDC's HIV Basics Date last updated: May 14, 2018

https://www.hiv.gov/hiv-basics/hiv-testing/learn-about-hiv-testing/understanding-hiv-test-results

# **Chapter IV. HIV Testing**

### B. Just Diagnosed: What's Next? 1. Living with HIV

Today, an estimated 1.1 million people are living with HIV in the United States. Thanks to better treatments, people with HIV are now living longer—and with a better quality of life—than ever before. If you are living with HIV, it's important to make choices that keep you healthy and protect others.

### Stay Healthy

You should start medical care and begin <u>HIV treatment</u> as soon as you are diagnosed with HIV. Taking medicine to treat HIV, called antiretroviral therapy (ART) is recommended for all people with HIV. Taking medicine to treat HIV slows the progression of HIV and helps protect your immune system. The medicine can keep you healthy for many years and greatly reduces your chance of transmitting HIV to sex partner(s) if taken the right way, every day.



Download CDC's Living With HIV 101 Consumer Info Sheet (PDF 578 KB)

If you're taking medicine to treat HIV, visit your health care provider regularly and always take your medicine as directed to keep your viral load (the amount of HIV in the blood and elsewhere in the body) as low as possible.

Visit CDC's *HIV Treatment Works* to find information on getting in care and staying in care if you have HIV.

#### **Do Tell**

It's important to disclose your HIV status to your sex and needle-sharing partner(s) even if you are uncomfortable doing it. Communicating with each other about your HIV status allows you and your partner to take steps to keep both of you healthy.

Many resources can help you learn ways to disclose your status to your partner(s). For tips on how to start the conversation with your partner, check out CDC's *Let's Stop HIV Together* and *Start Talking. Stop HIV.* campaigns.

Also, ask your health department about free partner notification services. Health department staff can help find your sex or needle-sharing partner(s) to let them know they may have been exposed to HIV and provide them with testing, counseling, and referrals for other services. These partner notification services will not reveal your name unless you want to work with them to tell your partners.

Many states have <u>laws</u> that require you to tell your sexual partners if you're HIVpositive before you have sex (anal, vaginal, or oral) or tell your needle-sharing partners before you share drugs or needles to inject drugs. In some states, you can be charged with a crime if you don't tell your partner your HIV status, even if your partner doesn't become infected.

## **Get Support**

Receiving a diagnosis of HIV can be a life-changing event. But having HIV is by no means a death sentence. Pay attention to your mental health. People can feel many emotions—sadness, hopelessness, and even anger. Allied health care providers and social service providers, often available at your health care provider's office, will have the tools to help you work through the early stages of your diagnosis and begin to manage your HIV.

Talking to others who have HIV may also be helpful. Find a local HIV support group. Learn about how other people living with HIV have handled their diagnosis.

You can view stories and testimonials of how people are living well with HIV at *Positive Spin* or on the websites for CDC's *Let's Stop HIV Together* and *HIV Treatment Works*. You can also find many other resources on *HIV Treatment Works* for people living with HIV.

## **Reduce the Risk to Others**

HIV is spread through certain body fluids from an HIV-infected person: blood, semen, pre-seminal fluid, rectal fluids, vaginal fluids, and breast milk. In the United States, HIV is most often <u>transmitted</u> by having anal or vaginal sex with someone who has HIV without using a condom or taking medicines to prevent or treat HIV. In addition, <u>a</u> <u>mother can pass HIV to her baby</u> during pregnancy, during labor, through breastfeeding, or by pre-chewing her baby's food.

The higher your viral load, the more likely you are to transmit HIV to others. When your viral load is very low (called viral suppression, with fewer than 200 copies per milliliter of blood) or undetectable (about 40 copies per milliliter of blood), your chance of transmitting HIV is greatly reduced. However, this is true only if you can stay virally suppressed. One thing that can increase viral load is not taking HIV medicines the right way, every day.

You can also protect your partners by <u>getting tested</u> and treated for other STDs. If you have both HIV and some other STD with sores, like syphilis, your risk of transmitting HIV can be about 3 times as high as if you didn't have any STD with sores.

<u>Taking other actions</u>, like using a condom the right way every time you have sex or having your partners take daily medicine to prevent HIV (called <u>pre-exposure</u>

prophylaxis or PrEP) can lower your chances of transmitting HIV even more. <u>Learn</u> the right way to use male condom.

#### Read more about medicines (antiretroviral treatments) for people living with HIV.

<u>Read more on HIV and opportunistic infections</u> (infections that are more frequent or more severe because of immunosuppression in HIV-infected persons).

Content Source: <u>HIV.gov</u> Date last updated: May 15, 2017

## 2. Talking About Your HIV Status

#### Should You Tell Other People about Your Positive Test Result?

It's important to share your status with your sex partner(s) and/or people with whom you inject drugs. Whether you disclose your status to others is your decision.

#### Partners

It's important to disclose your HIV status to your sex partner(s) and anyone you shared needles with, even if you are not comfortable doing it. Communicating with each other about your HIV status means you can take steps to keep both of you healthy.

The more practice you have disclosing your HIV status, the easier it will become. Many resources can help you learn ways to disclose your status to your partners. For tips on how to start the conversation with your partner(s), check out CDC's *Start Talking. Stop HIV.* campaign.

If you're nervous about disclosing your test result, or you have been threatened or injured by a partner, you can ask your doctor or the local health department to help you tell your partner(s) that they might have been exposed to HIV. This type of assistance is called partner notification or partner services. Health departments do not reveal your name to your partner(s). They will only tell your partner(s) that they have been exposed to HIV and should get tested.

Many states have <u>laws</u> that require you to tell your sexual partners if you're HIVpositive before you have sex (anal, vaginal, or oral) or tell your drug-using partners before you share drugs or needles to inject drugs. In some states, you can be charged with a crime if you don't tell your partner your HIV status, even if you used a condom or another type of protection and the partner does not become infected.

## Health Care Providers

Your health care providers (doctors, clinical workers, dentists, etc.) have to know about your HIV status in order to be able to give you the best possible care. It's also important that healthcare providers know your HIV status so that they don't prescribe medication for you that may be harmful when taken with your HIV medications.

Some states require you to disclose your HIV-positive status before you receive any health care services from a physician or dentist. For this reason, it's important to discuss the <u>laws in your state</u> about disclosure in medical settings with the healthcare provider who gave you your HIV test results.

Your HIV test result will become part of your medical records so that your doctor or other healthcare providers can give you the best care possible. All medical information, including HIV test results, falls under strict confidentiality laws such as the <u>Health Insurance Portability and Accountability Act's (HIPAA) Privacy Rule</u> and cannot be released without your permission. There are some limited exceptions to confidentiality. These come into play only when not disclosing the information could result in harm to the other person.

## Family and Friends

In most cases, your family and friends will not know your test results or HIV status unless you tell them yourself. While telling your family that you have HIV may seem hard, you should know that disclosure actually has many benefits—studies have shown that people who disclose their HIV status respond better to treatment than those who don't.

If you are under 18, however, some states allow your health care provider to tell your parent(s) that you received services for HIV if they think doing so is in your best interest. For more information, see the Guttmacher Institute's <u>State Policies in Brief:</u> <u>Minors' Access to STI Services</u>.

## Employers

In most cases, your employer will not know your HIV status unless you tell them. But your employer does have a right to ask if you have any health conditions that would affect your ability to do your job or pose a serious risk to others. (An example might be a health care professional, like a surgeon, who does procedures where there is a risk of blood or other body fluids being exchanged.)

If you have health insurance through your employer, the insurance company cannot **legally** tell your employer that you have HIV. But it is possible that your employer could find out if the insurance company provides detailed information to your employer about the benefits it pays or the costs of insurance.

All people with HIV are covered under the Americans with Disabilities Act. This means that your employer cannot discriminate against you because of your HIV status as long as you can do your job. To learn more, see the <u>Department of Justice's ADA.gov/HIV</u> website.

It may help you to hear stories about how others are living with HIV and how they've shared their status with partners, family, and friends. Visit *Positive Spin* or CDC's websites for *Let's Stop HIV Together* and *HIV Treatment Works*.

For more information about sharing your HIV status, visit CDC's *HIV Treatment Works* campaign's content on sharing your status.

Learn more about how to protect yourself and your partners, and get information tailored to meet your needs from CDC's <u>HIV Risk Reduction Tool</u> (BETA).

**Content Source:** <u>CDC's HIV Basics</u> **Date last updated:** May 15, 2017

## **Chapter V. Starting HIV Care**

# A. Find a Provider1. Locate an HIV Care Provider

How Do You Find an HIV Health Care Provider?

You can find an HIV health care provider by using our HIV Testing Sites and Care Services Locator. Just enter your Zip code to be connected to HIV medical care and other services such as HIV testing locations, housing assistance, and substance abuse and mental health services.

There are other ways to find HIV providers and services too:

- 1. **Ask your primary care provider**—If you have a primary care provider (someone who manages your regular medical care), that person may have the medical knowledge to treat your HIV. If not, he or she can refer you to a provider who specializes in providing HIV care and treatment.
- 2. **Call your state HIV/AIDS hotline**—State HIV/AIDS toll-free hotlines are available to help connect you to agencies that can help determine what services you are eligible for and help you get them.
- 3. **Search the Referral Link directory**—The American Academy of HIV Medicine's Referral Link is a directory of healthcare providers specializing in HIV management and prevention across the country. The doctors and clinicians represented in this database practice in a variety of care settings including health centers, Ryan White clinics, and private practices.
- 4. **Use your home HIV test hotline**—If you received an HIV diagnosis by using an HIV home test kit, it is important that you take the next steps to make sure your test result is correct. Home test manufacturers provide confidential counseling to answer questions and provide local referrals for follow-up testing and care.

## Why Do You Need to Find an HIV Health Care Provider?

After you're diagnosed with HIV, it's important to see a health care provider who can help you start HIV medication (called antiretroviral therapy or ART) as soon as possible.

ART is recommended for all people with HIV, regardless of how long they've had the virus or how healthy they are. ART can't cure HIV, but it can control the virus. If taken as every day, exactly as prescribed, ART can reduce the amount of HIV in your body (also called the viral load) to a very low level. This is called viral suppression. Viral suppression helps to keep you healthy and prevents illness.

If your viral load is so low that it doesn't show up in a standard lab text, this is called having an undetectable viral load.

There are important health benefits to having a suppressed or undetectable viral load. People living with HIV who know their status, take HIV medication daily as prescribed, and get and keep an undetectable viral load can live long and healthy lives.

There is also a major prevention benefit. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of transmitting HIV to their HIV-negative sexual partners. This is often called treatment as prevention.

## How Soon Do You Need to Find an HIV Health Care Provider?

The U.S. Department of Health and Human Services (HHS) guidelines on the use of HIV medicines in adults and adolescents recommend that people with HIV start medical care and begin HIV treatment as soon as possible. If you have the following conditions, it's especially important to start ART right away: pregnancy, AIDS, certain HIV-related illnesses and coinfections, and early HIV infection. (Early HIV infection is the period up to 6 months after infection with HIV.) Learn more about when to start ART.

Content Source: HIV.gov Date last updated: April 29, 2019

## 2. Types of Providers

## Who Should Be on My Health Care Team?

Finding a health care team that is knowledgeable about HIV care is an important step in managing your care and treatment. If you are able to choose your provider, you should look for someone who has a great deal of experience treating HIV. This matters because the more HIV experience your provider has, the more familiar he or she will be with the full range of treatment options that exist today, as well as the unique issues that can come up in HIV care over time.

Who is on your HIV health care team will depend on your health care needs and the way that the health care system, clinic, or office you will get your care from is set up. It should also be based on your preferences and what will work best for you. Don't get hung up on finding the perfect provider the first week after you are diagnosed. The most important thing you can do now for your health is to meet with an HIV provider who can order your first lab tests and start HIV treatment as soon as possible. Don't let

the search for the perfect doctor slow you down on this. You can change doctors later if you need to.

Your HIV health care provider should lead your health care team. That person will help you determine which HIV medicines are best for you, prescribe antiretroviral therapy (ART), monitor your progress, and partner with you in managing your health. He or she can also help put you in touch with other types of providers who can address your needs. Your primary HIV health care provider may be a doctor of medicine (MD) or doctor of osteopathic medicine (DO), nurse practitioner (NP), or a physician assistant (PA). Some women may prefer to see an OB-GYN provider who has expertise in HIV/AIDS. On the whole, the patients of providers with more experience in HIV care tend to do better than those who see a provider who only has limited HIV care experience.

In addition to your HIV health care provider, your health care team may include other health care providers, allied health care professionals, and social service providers who are experts in taking care of people living with HIV.



The types of professionals who may be involved in your HIV care include:

#### Health care providers

- **Medical doctors (MD or DO):** Health care professionals who are licensed to practice medicine.
- **Nurse practitioners (NP):** Registered nurses, with specialized graduate education, who can diagnose and treat illnesses independently, or as part of a health care team.
- **Physician assistants (PA):** Health care professionals who are trained to examine patients, diagnose injuries and illnesses, and provide treatment to patients under the supervision of physicians and surgeons.

#### Allied health care professionals:

- **Nurses:** Health care professionals who provide and coordinate patient care as part of a health care team.
- **Mental health providers:** Professionals, such as a counselor, psychologist, or psychiatrist, who provide mental health care in the form of counselling or other types of therapy.
- **Pharmacists:** Health care professionals who provide prescription medicines to patients and offer expertise in the safe use of prescriptions. Pharmacists may also provide advice on how to lead a healthy life; conduct health and wellness screenings; provide immunizations; and oversee medicines given to patients.
- **Nutritionists/dietitians:** Experts in food and nutrition who advise people on what to eat in order to lead a healthy lifestyle or achieve a specific health-related goal.
- **Dentists:** Health care professionals who diagnose and treat problems with a person's teeth, gums, and related parts of the mouth. Dentists also provide advice and instruction on taking care of teeth and gums and on diet choices that affect oral health.

#### Social service providers:

- **Social workers:** Professionals who help people solve and cope with problems in their everyday lives.
- **Case managers:** Professionals who help people find the support and services they need, develop a services plan, and follow up to make sure that services are provided.
- **Substance use/abuse specialists:** Counselors who provide advice, treatment, and support to people who have problems with substance use.

**Patient navigators:** There are a number of different types of navigators who are trained and culturally sensitive workers who provide support and guidance to people

by helping them "navigate" through the health care system. For example, navigators could be health care workers, social workers, those who work for community-based organizations, or peers.

**Content Source:** CDC's HIV Treatment Works **Date last updated:** May 21, 2018

## 3. Take Charge of Your Care

#### How Can You Work Best with Your Health Care Team?

HIV treatment is most successful when you actively take part in your medical care. That means taking your HIV medications every time, at the right time, and in the right way; keeping your medical appointments; and communicating honestly with your health care provider. This can be achieved when you:

- **Keep all of your medical appointments.** There are many tools you can use to help you remember and prepare for your appointments. You can:
  - Use a calendar to mark your appointment days.
  - Set reminders on your phone.
  - Download a free app from the Internet to your computer or smartphone that can help remind you of your medical appointments. Search for "reminder apps" and you will find many choices.
  - Keep your appointment card reminder in a place where you will see it often, such as on a mirror, or on your refrigerator.
  - $_{\odot}$   $\,$  Ask a family member or friend to help you remember your appointment.
- **Be prepared for your medical appointments.** Before an appointment, write down questions or concerns you want to discuss with your health care provider. Be prepared to write down the answers you receive during your visit.
  - If you can't keep a scheduled appointment, contact your provider to let them know, and make a new appointment as soon as possible.
- **Communicate openly and honestly with your health care providers.** Your health care provider needs to have the most accurate information to manage your care and treatment.
- **Keep track of your medical services.** You may have multiple health care providers working on your health care team. Keep records of your lab results, medical visits, appointment dates and times, medicines and medicine schedules, and care and treatment plans.

• **Update your contact information.** Make sure your health care providers have your correct contact information (telephone number, address, and e-mail address) and let them know if any contact information changes.

Need inspiration? You can view stories and testimonials of people living with HIV who are working with their health care team to stay in care and on treatment by visiting *Positive Spin* or by visiting CDC's *HIV Treatment Works* campaign.

Content Source: <u>CDC's HIV Treatment Works</u> Date last updated: May 15, 2017

## **Chapter V. Starting HIV Care**

# B. Getting Ready for Your First Visit 1. What to Expect at Your First HIV Care Visit

#### What Can You Expect at Your Medical Visits?

Living with HIV can be challenging at times. Partnering with your health care provider will help you manage your health and HIV care.

During your medical appointments, your health care provider may:

- Conduct medical exams to see how HIV is affecting your body.
- Ask you questions about your health history.
- Take a blood sample to check your CD4 count and viral load.
- Look for other kinds of infections or health problems that may weaken your body, make your HIV infection worse, or prevent your treatment from working as well as possible.
- Give you immunizations, if you need them.
- Discuss, prescribe, and monitor your HIV medicines, including when and how to take them, possible side effects, and continued effectiveness.
- Discuss strategies that will help you follow your HIV treatment plan and maintain your treatment.

- Help identify additional support you may need, such as: finding a social worker, case manager or patient navigator; finding an HIV support group; finding support services for mental health or substance use issues; or finding support services for transportation or housing.
- Ask you about your sex partner(s) and discuss ways to protect them from getting HIV.
- Ask you about your plans, or your partner's plans, for getting pregnant.

Talk regularly with your health care provider about how you are feeling and communicate openly and honestly. Tell your health care provider about any health problems you are having so that you can get proper treatment. Discuss how often you should expect to attend medical visits. Staying informed about HIV care and treatment advances and partnering with your health care provider are important steps in managing your health and HIV care.

## What Tests Can Help Monitor Your HIV Infection?

Your health care provider will use blood tests to monitor your HIV infection. The results of these blood tests, which measure the amount of HIV virus and the number of CD4 cells in your blood, will help you and your health care provider understand how well your HIV treatment is working to control your HIV infection. These test results will also help your health care provider decide whether he or she should make changes to your treatment.

These blood tests include regular CD4 counts and viral load tests. Read about these tests below.

## CD4 Count

CD4 cells, also called T-cells, play an important role in your body's ability to fight infections. Your CD4 count is the number of CD4 cells you have in your blood. When you are living with HIV, the virus attacks and lowers the number of CD4 cells in your blood. This makes it difficult for your body to fight infections.

Typically, your health care provider will check your CD4 count every 3 to 6 months. A normal range for a CD4 cell count is 500 cells to 1,600 cells per cubic millimeter of blood (you may see this written as "cells/mm3"). A low CD4 cell count means you are at higher risk of developing opportunistic infections. These infections take advantage of your body's weakened immune system and can cause life-threatening illnesses. A higher CD4 cell count means that your HIV treatment is working and controlling the

virus. As your CD4 count increases, your body is better able to fight infection. If you have a CD4 count of fewer than 200 cells per cubic millimeter of blood, you will be diagnosed as having AIDS.

## Viral Load Test

Your viral load is the amount of HIV in your blood. When your viral load is high, you have more HIV in your body, and your immune system is not fighting HIV as well.

When you take a viral load test, your health care provider looks for the number of HIV virus particles in a milliliter of your blood. These particles are called "copies."

The goal of HIV treatment is to help move your viral load down to undetectable levels. In general, your viral load will be declared "undetectable" if it is under 40 to 75 copies in a sample of your blood. The exact number depends on the lab that analyzes your test.

Your health care provider will use a viral load test to determine your viral load. A viral load test will:

- Show how well your HIV treatment is controlling the virus, and
- Provide information on your health status.

You should have a viral load test every 3 to 6 months, before you start taking a new HIV medicine, and 2 to 8 weeks after starting or changing medicines.

**Content Source:** CDC's HIV Treatment Works **Date last updated:** May 15, 2017

## Chapter VI. Staying in HIV Care

## A. Provider Visits and Lab Tests:

1. Making Care Work for You

#### What Are the Benefits of Staying in HIV Medical Care?

HIV treatment is a lifelong commitment to your health and well-being. People who are newly diagnosed with HIV often find it overwhelming. But HIV is a manageable disease. People living with HIV who <u>take their HIV medications</u> every day exactly as prescribed and achieve and maintain a suppressed viral load can live long and healthy lives and have effectively no risk of transmitting the virus to their sexual partners.

## See Your HIV Health Care Provider Regularly

Part of keeping the virus in check and staying healthy is <u>seeing your HIV health care</u> <u>provider regularly</u>—usually a couple of times a year, depending on your health.

At your HIV medical care appointments, your provider will run blood tests to monitor your HIV infection and make sure your HIV medication is working properly. He or she will also treat you for other health concerns you may have, and help connect you to resources to help you with other issues that could affect your ability to stick to your HIV treatment plan.

If you don't have a provider or want to find a new one, get <u>tips on how to locate an HIV</u> <u>health care provider</u>.

## How Can You Make the Most of Your Medical Care?

HIV care and treatment is most successful when you actively take part. That means taking your HIV medications as prescribed, keeping your medical appointments, and communicating honestly with your health care provider. However, health care providers know that taking HIV medication every day and seeing a HIV health care provider regularly can be difficult for some people. For example, some people may experience <u>side effects</u> from medication. Others may have trouble taking their medication on time given a busy work schedule. If you're having trouble taking your HIV medication and staying in medical care, talk to your provider right away. Together you can identify the reasons and make a plan to address them.

You can find the support and assistance you need. For example, you might find it useful to join a support group with other people living with HIV. Or your HIV care team might be able to connect you to a peer mentor who has been down this road and can share lessons and perspectives that might be helpful. Many HIV care teams also offer case management services to help connect you to other supportive services that can help you overcome other obstacles to remaining in regular HIV medical care.

Taking the steps that are necessary for you to get control over the virus will make it easier for you to put more time and energy toward the other parts of your life. Once you find a strategy works for you, HIV can become a routine part of your life. If unexpected things happen that make it harder to manage life with HIV again, step back and think about what has changed. Don't be too hard on yourself and give up. Get support from others and learn from their experiences. Think about some of the barriers that you have already overcome, and remind yourself of your strengths and abilities.

You can make HIV care work for you. Some of the other information on this site may be useful to you in figuring this out, especially the information about <u>HIV</u> <u>treatment</u>, <u>mental health</u>, <u>substance use</u> and <u>other topics related to living well with</u> <u>HIV</u>.

**Content Source:** <u>HIV.gov</u> **Date last updated:** September 27, 2018

## 2. Seeing Your Health Care Provider

## **Managing Your Appointments**

HIV is a treatable condition. If you are diagnosed early, get on antiretroviral therapy (ART), and adhere to your medication, you can stay healthy, live a normal life span, and reduce the chances of transmitting HIV to others. Part of staying healthy is seeing your HIV care provider regularly so that he or she can track your progress and make sure your HIV treatment is working for you.

Your HIV care provider might be a doctor, nurse practitioner, or physician assistant. Some people living with HIV go to an HIV clinic; others see an HIV specialist at a community health center, Veterans Affairs clinic, or other health clinic; and some people see their provider in a private practice. Current guidelines recommend that most people living with HIV see their provider for lab tests every 3 to 4 months. Some people may see their provider more frequently, especially during the first two years of treatment or if their HIV viral load is not suppressed (i.e. very low or undetectable). Current guidelines say that people who take their medication every day and have had a suppressed viral load at every test for more than 2 years only need to have their lab tests done two times a year.

In addition to seeing your HIV care provider, you may need to see other health care practitioners, including dentists, nurses, case managers, social workers, psychiatrists/psychologists, pharmacists and medical specialists. This may mean juggling multiple appointments, but it is all part of staying healthy. You can help make this easier by preparing a plan for yourself.

## Before Your Visit

For many people living with HIV, appointments with their HIV care provider become a routine part of their life. These tips may help you better prepare for your visits to your HIV care provider and get more out of them:

- Start with a list or a notebook. Write down any questions you have before you go. (The Department of Veterans Affairs offers a useful list of sample questions you can bring with you.)
- Make a list of your health and life goals so that you can talk about them with your HIV provider and how she/he can help you reach them.
- Make a list of any symptoms or problems you are experiencing that you want to talk to your provider about.
- Bring a list of all the HIV and non-HIV medications that you are taking (or the medications themselves), including over-the-counter medications, vitamins, or supplements. Include a list of any HIV medications you may have taken in the past and any problems you had when taking them.
- Bring along a copy of your medical records if you are seeing a new provider who does not already have them. You have the right to access your medical records and having copies of your records can help you keep track of your lab results, prescriptions, and other health information. It can also help your new provider have a better understanding of your health history. For more details on this, see the Information Is Powerful Medicine campaign site.
- Be prepared to talk about any changes in your living situation, relationships, insurance, or employment that may affect your ability to keep up with your HIV appointments and treatment or to take care of yourself. Your provider may be able to connect you with resources or services that may assist you.
- Be on time. Most healthcare providers have full appointment schedules—if you are late, you throw the schedule off for everyone who comes after you. If you are late, there is a chance your provider will not be able to see you the same day.

## During Your Visit

• If your provider wants to run some lab tests during your visit, make sure you understand what the lab tests are for and what your provider will do with the results. If you don't understand, ask your provider to explain it in everyday terms. Typically, you will be asked to give a sample (blood, urine) during your

visit and your provider's office will call you with your results in a few days. Keep track of your results and call your provider back if you have any questions.

- Be honest. Your provider isn't there to judge you, but to make decisions with you based on your particular circumstances. Talk about any HIV medication doses you have missed. Tell your provider about your sexual or alcohol/drug use history. These behaviors can put you at risk of developing drug resistance and getting other sexually transmitted infections (STIs) as well as hepatitis. Your provider will work with you to develop strategies to keep you as healthy as possible.
- Describe any side effects you may be having from your HIV medications. Your provider will want to know how the HIV medications are affecting your body in order to work with you to solve any problems and find the right combination of medications for you.
- Ask your provider about your next visit and what you should bring to that appointment.
- Ask for a list of your upcoming appointments when you check out. Work with your case manager, if you have one, to develop a system to help you remember your appointments, such as a calendar, app, or text/e-mail reminders.

## Asking Questions and Solving Problems

It's important for you to be an active participant in your own health care and it's your right to ask questions. You may need to direct your questions to different people, depending on what you need/want to know:

- HIV care providers (doctors, nurse practitioners, physician assistants) can answer specific questions about a wide range of issues that affect your health. They can also help you find resources and solutions to problems you may have that affect your health, including:
  - Your prognosis (how your HIV disease is affecting your body)
  - How to manage any symptoms you may be experiencing
  - Medication issues, including medication changes, new medications, and how the HIV medications may interact with other medications you take.
  - Sexual health issues, including questions about any sexual symptoms you may be having, and how you can prevent or treat STIs, and how you can prevent transmitting HIV to your partner(s).
  - Family planning considerations, including your goals; birth control options for you and/or your partner, if relevant; your options for having children should you wish to do so; and, if you are an HIV-positive woman

who is pregnant or considering getting pregnant, how you can reduce the risk of transmitting HIV to your baby

- Substance use issues, including how alcohol/drug use can affect your HIV treatment and overall health, and whether you should be referred for substance abuse treatment
- Mental health issues, including questions about any mental health symptoms you may be having, and whether you should be referred for mental health treatment
- Referrals for other medical issues you may be experiencing
- The meaning of lab test results
- The need for surgical procedures, if relevant
- Medication adherence strategies (tips for keeping up with your medication and ensuring you take it as scheduled and exactly as prescribed)
- Any clinical trials or research studies that may be relevant for you
- Information about resources and services that can help you with issues or challenges you may be having that affect your health.
- Nurses and case managers often have more time to answer questions about what you discuss with your provider and to help identify solutions to problems that are affecting your health, particularly around:
  - Understanding your HIV treatment plan, including how many pills of each medicine you should take; when to take each medicine; how to take each medicine (for example, with or without food); and how to store each medicine
  - Understanding possible side effects from your HIV medication and what you should do if you experience them
  - Challenges you may have in taking your medications and/or keeping your medical appointments, and strategies for overcoming these challenges
  - Resources to help you better understand lab reports, tests, and procedures
  - Mental health and/or substance abuse treatment, housing assistance, food assistance, and other resources that exist in your community
  - Insurance and pharmacy benefits, and other aspects of paying for care (for more on this, see Paying for Care and Treatment)
  - Understanding other medical conditions you may have
  - How to quit smoking and resources that are available to assist you

 Information about resources and services that can help you with issues or challenges you may be having that affect your health.

## Dental Appointments

Dental visits are an extremely important part of your care when living with HIV. Many signs of HIV infection can begin in the mouth and throat, and people with HIV are more likely to develop some serious dental problems. For these reasons, it is important to see a dentist regularly.

Tips for your dental visit:

- Make sure you have routine dental visits for cleaning and check-ups. Preventing problems before they occur is always the best approach.
- Tell your dentist you have HIV. That's not because your dentist will need to take additional precautions—all healthcare professionals use "universal precautions" to prevent the transmission of bloodborne diseases to patients and vice versa. Rather, it will help the dentist know to look for particular oral health problems that you might be at risk for.
- Don't wait for problems in your mouth to get out of hand. When you notice something wrong (such as tooth pain or a mouth sore), call your dentist right away.
- Be on time for your dental visit. Try not to miss your appointment, if you can help it—and if you can't, reschedule it ASAP.
- Keep a record of your dental visits, just like you do with your visits to your HIV care provider. Keep track of when you had dental X-rays (and what was X-rayed), any procedures or treatments you had, and when your next visit is scheduled.
- Bring copies of your recent test results and lab reports. Your dentist may need to have information about your CD4 count and platelet count to know how best to treat your dental issue. Also bring a list of any medications you are currently taking, as your dentist needs to know what you are taking to avoid giving you other medications which may have bad interactions.
- Know your rights: Any dentist licensed in the United States should be able to provide at least basic dental care to people living with HIV. If you sense there is discrimination towards you based on your HIV status, there are resources to help you with this (For more information, see the U.S. Department of Justice Civil Rights Division's ADA.gov/hiv.)

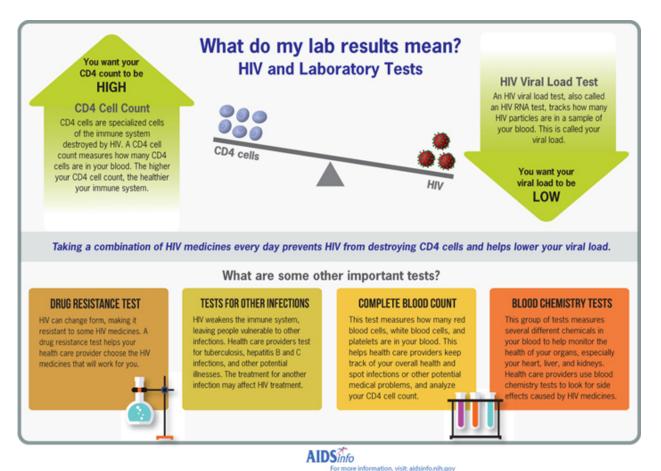
Content Source: HIV.gov Date last updated: May 15, 2017

## 3. Lab Tests and Results

#### Lab Tests and Why They Are Important

As part of your HIV care, your provider will order several laboratory tests. The results of these lab tests, along with your physical exam and other information you provide, will help you and your provider work together to develop the best plan to manage your HIV care so that you can get the virus under control, protect your health, and reduce the chance that you will pass the virus to others.

Your healthcare provider will repeat some of these tests as part of your ongoing HIV care to continue to assess your health and how well your HIV treatment is working.



The lab tests may include:

• **CD4 count**: CD4 cells are a type of white blood cell. They are specialized cells of the immune system that are destroyed by HIV. A CD4 count measures how many CD4 cells are in your blood. The higher your CD4 cell count, the healthier your immune system. The CD4 count of an uninfected adult/adolescent who is generally in good health ranges from 500 cells/mm<sup>3</sup> to 1,600 cells/mm<sup>3</sup>. In contrast, if HIV has destroyed so many CD4 cells that you have a CD4 count of fewer than 200/mm<sup>3</sup>, you are considered to have progressed to stage 3 (AIDS), the most advanced stage of HIV infection.

**Why it's important**: A CD4 count is a good measure of your risk of <u>opportunistic</u> <u>infections</u> and an indicator of how well your immune system is working. Treatment with antiretroviral therapy (ART), medications that control the HIV, is recommended for everyone with HIV, no matter how high or low their CD4 count is. However, a low CD4 count (below 200/mm<sup>3</sup>) increases the urgency to start ART.

• **CD4 Percentage**: This measures how many of your white blood cells are actually CD4 cells. This measurement is more stable than CD4 counts over a long period of time, but, for most people, the CD4 count remains a more reliable measure of how well your immune system is working than the CD4 percentage.

**Why it's important**: This measurement is less likely to vary in between blood tests than CD4 counts (which can vary from month to month or day to day).

- Viral Load (VL): An HIV viral load test, also called an HIV RNA test, tracks how many HIV particles are in a sample of your blood. This is called your viral load.
   Why it's important: A goal of HIV treatment is to keep your viral load so low that the virus can't be detected by a viral load test. It's important to get a viral load test to see the level of HIV in your blood before starting treatment and help guide the choice of HIV medications and then to get repeat tests to track your response to HIV treatment.
- Complete Blood Count (CBC): This is a measure of the concentration of red blood cells, white blood cells, and platelets in a sample of your blood.
   Why it's important: A CBC is one of the most commonly ordered blood tests. It can reveal infections, anemia (abnormality in your red blood cells), and other medical issues.
- **Drug Resistance Tests:** HIV can change form, making it resistant to some HIV medicines. A <u>drug resistance test</u> helps your provider identify which, if any, HIV medicines will not be effective against the strain of HIV you have.

**Why it's important:** Drug resistance test results help your provider determine which HIV medicines are most likely to work for you.

• **Serum Chemistry Panel**: This panel is comprised of a series of several blood tests and helps provide information about your body's metabolism. It gives your provider information about how your kidneys and liver are working, and can be used to evaluate your blood sugar levels, calcium levels, and phosphorous levels.

**Why it's important**: Some HIV medications can have serious side effects, and this test helps your provider monitor the impact of your medications on your body's ability to function normally.

- Sexually Transmitted Disease (STD) Screening: These screening tests check for <u>syphilis, gonorrhea and chlamydia</u>.
   Why it's important: STDs can also cause serious health problems if not treated Having an STD also can increase your risk of transmitting HIV to others.
- **PAP Test (Cervical and Anal)**: A <u>cervical Pap test</u> (or Pap smear) looks for cancers and precancers in a woman's cervix. The cervix is the lower part of a woman's uterus (womb), which opens into the vagina. The test involves using a swab to take cell samples directly from the cervix. An anal Pap test can be done on a male or female; it involves a swab to take a cell sample from the anal canal.

**Why it's important**: For women living with HIV, abnormal cell growth in the cervix is common, and abnormal anal cells are common for both men and women living with HIV. These abnormal cells may become cancerous if they aren't treated.

Hepatitis A, B, and C Tests: These blood tests check for current or past infection with Hepatitis A, B, or C.
 Why it's important: Some people who are living with HIV are also coinfected with hepatitis. Checking you for hepatitis A, B, and C infection can help your

provider to determine if you need to be treated, or if you are a candidate for one of the existing hepatitis A or B vaccines. (Read more about how <u>hepatitis</u> <u>affects</u> people living with HIV.)

Tuberculosis Test: This blood test checks for TB infection. If the TB blood test is not available, a TB skin test should be performed.
 Why it's important: Untreated TB can be a deadly disease for people living

with HIV. Early screening and treatment will help limit your risk of severe illness, as well as lower your chances of transmitting TB to others if you do have it.

• **Toxoplasmosis Screening**: This test checks for past exposure to a parasite that can cause severe damage to the brain, eyes, and other organs in people with weakened immune systems.

**Why it's important**: Toxoplasmosis can be a deadly <u>opportunistic infection</u> for people living with HIV. Your clinician needs to know if you have been exposed to the parasite that causes toxoplasmosis or are at risk for exposure. This will help your healthcare provider to decide if you need preventive treatment. If your CD4 count falls below 100/mm<sup>3</sup>, you will probably need to do another screening, even if your earlier screens were negative.

• **Fasting Lipid Panel (Cholesterol and Triglycerides)**: Lipids are fat or fat-like substances found in the blood and body tissues. These tests measure your lipid levels, including cholesterol and triglycerides. You should not to eat for several hours before these blood tests.

**Why it's important**: Some HIV medications can affect your cholesterol levels and the way your body processes and stores fat. High lipids can make you prone to other medical problems, including heart problems. It's important to know what your lipids are before starting treatment to help guide the choice of medications and to treat high lipids to avoid other serious health problems.

• **Fasting Glucose (blood sugar) Test**: This test measures your blood sugar levels to check for signs of diabetes. You should not to eat for several hours before this blood test.

**Why it's important**: Some HIV medications can affect blood sugar levels, potentially leading to complications like diabetes. It's important to get a glucose test to know what your blood sugar is before starting treatment to help guide the choice of HIV medications and then to get repeat tests to monitor possible increases in your blood glucose. (Read more about <u>diabetes</u> and people living with HIV.)

• **Pregnancy Test:** This test shows whether a woman is pregnant or not. **Why it's important:** If you are pregnant, you can greatly lower your risk of passing HIV to your baby and protect your own health by taking ART during pregnancy, labor, and delivery. You and your health care provider can discuss steps you can take prevent transmitting HIV to your baby. **Content Source:** <u>HIV.gov</u> **Date last updated:** February 14, 2017

## 4. Returning to Care

#### What Should You Do If You've Stopped Going to HIV Care?

If you've stopped seeing your health care provider regularly for HIV care or have stopped taking your medication, it's important to return to care, even if you have to start seeing a new provider.

HIV is a serious health condition. If you stop taking your HIV medication or haven't seen a health care provider recently for a test to know if your medication is working, you are giving HIV the chance to multiply quickly. This could weaken your immune system, and you could become very sick. You could also develop resistance your HIV medications, and they will no longer be as effective.

Some people living with HIV who stop seeing their health care provider worry about going back and how their provider will react. But providers are usually concerned when their patients stop coming to appointments and are happy to see them return to care.

Talk openly and honestly with your provider. Discuss the reasons why you haven't kept up with your appointments and/or have stopped taking your HIV medications so that he or she can help you find ways to address those reasons in the future.

And if you don't like your health care provider, find a new one. Your new provider can help you ask for your health records to be transferred over from your previous provider.

**Remember: Being in care and taking your HIV medication is the key to staying healthy.** You can manage your HIV and live a long, healthy life with regular medical care and HIV treatment.

#### Help Is Available

Reach out to a local HIV/AIDS service organization. They have lots of experience helping people who have left HIV care and want to return.

Many organizations have peer navigators. These are individuals from the community who are trained to guide you through the medical and social services you may need and provide support to help you stick to your HIV treatment plan. Many are living with HIV themselves and have learned a lot about how to make it easier to take medication and remain in care. They can relate to your experience and work with you to develop solutions to many problems you may encounter.

Many organizations also have case managers or benefits counselors who can help you determine what programs and services you may qualify for—as well as help you find support groups.

To find a local HIV/AIDS service organization near you, use the <u>HIV Testing and Care</u> <u>Services Locator</u>.

#### **Reasons People Stop Going to HIV Care**

There are many reasons why some people stop taking their HIV medication and stop seeing their health care provider regularly. These include medication side effects that are difficult to manage, changes in health care coverage, moving to different city or state, or other issues such as substance abuse or mental health disorders. Read about these challenges and how you might overcome them on our page, <u>Tips for Taking Your HIV Medications Every Day</u>.

Need inspiration to return to care? View the personal stories of people living with HIV who are living healthy with HIV. Visit <u>PositiveSpin.HIV.gov</u>.

Content Source: <u>HIV.gov</u> Date last updated: May 15, 2017

## **Chapter VI. HIV Treatment**

## B. HIV Treatment 1. HIV Treatment Overview

#### What Is HIV Treatment?

HIV treatment involves taking medicines that slow the progression of the virus in your body. HIV is a type of virus called a retrovirus, and the combination of drugs used to

treat it is called antiretroviral therapy (ART). ART is recommended for all people living with HIV, regardless of how long they've had the virus or how healthy they are. ART must be taken every day, exactly as your health care provider prescribes.

## Why Is HIV Treatment Important?

Getting and staying on HIV treatment because it reduces the amount of HIV in your blood (also called the viral load) to a very low level. This **keeps you healthy** and prevents illness. There is also a major **prevention benefit**. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIV-negative partners. This is called <u>treatment as prevention</u>.

If left untreated, HIV attacks your immune system and can allow different types of lifethreatening infections and cancers to develop. If your CD4 cell count falls below a certain level, you are at risk of getting an <u>opportunistic infection</u>. These are infections that don't normally affect people with healthy immune systems but that can infect people with immune systems weakened by HIV infection. Your health care provider may prescribe medicines to prevent certain infections.

HIV treatment is most likely to be successful when you know what to expect and are committed to taking your medicines exactly as prescribed. Working with your health care provider to develop a treatment plan will help you learn more about HIV and manage it effectively.

## When Should You Start HIV Treatment?

<u>Treatment guidelines</u> from the U.S. Department of Health and Human Services recommend that a person living with HIV begin ART **as soon as possible after diagnosis**. Starting ART slows the progression of HIV and can keep you healthy for many years.

If you delay treatment, the virus will continue to harm your immune system and put you at higher risk for developing <u>opportunistic infections</u> that can be life threatening.

## **Does ART Cause Side Effects?**

Like most medicines, antiretroviral therapy (ART) can cause side effects. However, not everyone experiences side effects from ART. The HIV medications used today have fewer side effects, fewer people experience them, and they are less severe than in the past. Side effects can differ for each type of ART medicine and from person to person. Some side effects can occur once you start a medicine and may only last a few days or weeks. Other side effects can start later and last longer.

If you experience side effects that are severe or make you want to stop taking your HIV medication, talk to your health care provider or pharmacist before you miss any doses or stop taking the medication. Skipping doses or starting and stopping medication can lead to <u>drug resistance</u>, which can harm your health and limit your future treatment options.

Some side effects of ART that are most commonly reported include:

- Nausea and vomiting,
- Diarrhea,
- Difficulty sleeping,
- Dry mouth,
- Headache,
- Rash,
- Dizziness,
- Fatigue, and
- Pain.

And be aware; HIV medicines also may cause different <u>side effects in women</u> than men.

Contact your health care provider or pharmacist immediately if you begin to experience problems or if your treatment makes you sick. If side effects make you want to skip taking your medications sometimes or stop taking them altogether, talk to your health care provider or pharmacist right away to find solutions that work for you. Your health care provider may prescribe medicines to reduce or eliminate side effects or may recommend changing your medication to another type of ART that might work better for you. Learn more about the possible side effects of ART and ways to manage them.

## What Is HIV Drug Resistance?

Drug resistance can be a cause of treatment failure for people living with HIV. As HIV multiplies in the body, it sometimes mutates (changes form) and produces variations of itself. Variations of HIV that develop while a person is taking ART can lead to drug-resistant strains of HIV.

With drug resistance, HIV medicines that previously controlled a person's HIV are not effective against new, drug-resistant HIV. In other words, the HIV medicines can't prevent the drug-resistant HIV from multiplying. Drug resistance can cause HIV treatment to fail.

A person can initially be infected with drug-resistant HIV or develop drug-resistant HIV after starting HIV medicines. Drug-resistant HIV also can spread from person to person. Drug-resistance testing identifies which, if any, HIV medicines won't be effective against your specific strain of HIV. Drug-resistance testing results help determine which HIV medicines to include in an <u>HIV treatment regimen</u>.

**Taking HIV medication every day, exactly as prescribed helps prevent drug resistance.** Read more about drug resistance in <u>this fact sheet</u> from AIDSinfo.

**Content Source:** <u>HIV.gov</u> **Date last updated:** March 29, 2019

## 2. Taking Your HIV Medication Every Day

#### Why Should You Take Your HIV Medication Every Day?

Taking your HIV medication daily as prescribed provides many benefits. Among them, it:

- Allows the HIV medication to reduce the amount of HIV in your body (also called the viral load) to a very low level. This is called viral suppression. If the viral load is so low that it doesn't show up in a standard lab test, this is called having an undetectable viral load. **Getting and keeping an undetectable viral load is the best thing you can do to stay healthy**.
- Helps protect your partners. If you take HIV medication every day, exactly as prescribed and get and keep an undetectable viral load, you have **effectively no risk of transmitting HIV to an HIV-negative partner through sex**. <u>This is</u> <u>called Treatment as Prevention</u>

Learn more: Read our fact sheet about the health and prevention benefits of viral suppression and maintaining an undetectable viral load (PDF 166 KB).

Taking your HIV medication daily is also important because skipping doses makes it easier for HIV to change form, causing your medication to stop working. This is

called <u>drug resistance</u>. HIV can become resistant to your medication and to similar medications that you have not yet taken. This limits your options for successful HIV treatment. Drug-resistant strains of HIV can be transmitted to others, too.

## What Should You Do If You Miss a Dose?

Taking your HIV medication every day, exactly the way your health care provider tells you to will help keep your viral load low and your <u>CD4 cell count</u> high. If you skip doses, even now and then, you are giving HIV the chance to multiply rapidly. This could weaken your immune system, and you could become sick.

Talk to your health care provider if you miss a dose. In most cases, if you realize you missed a dose, take the medicines as soon as you can, then take the next dose at your usual scheduled time (unless your pharmacist or health care provider has told you something different).

If you find you miss a lot of doses, talk to your health care provider or pharmacist about ways to help you remember your medicines. You and your health care provider may even decide to change your treatment regimen to fit your health care needs and life situation, which may change over time.

#### Do You Have to Take Your HIV Medication If Your Viral Load Is Undetectable?

Yes, antiretroviral therapy (ART) reduces your viral load, ideally to an undetectable level. If your viral load goes down after starting ART, then the treatment is working, and you should continue to take your medicine as prescribed. If you keep an undetectable viral load, you can stay healthy and have effectively no risk of transmitting HIV to an HIV-negative partner through sex.

**Content Source:** <u>HIV.gov</u> **Date last updated:** January 09, 2019

## 3. Tips on Taking Your HIV Medication Every Day

What Are Some Tips to Help Me Take My HIV Medication Every Day?

If you're newly diagnosed with HIV, you may be seeking tips and tools to help you keep up with your HIV treatment. That's because HIV treatment involves taking HIV medication **every day, exactly as prescribed** to lower the amount of HIV in your body (also called the viral load) to a very low level. This is called viral suppression. If the viral load is so low that it doesn't show up in a standard lab test, this is called having an undetectable viral load. Getting and keeping an undetectable viral load is the best thing you can do to stay healthy. There is also a prevention benefit: people living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of transmitting HIV to an HIV-negative partner through sex.

## Viral Suppression and Undetectable Viral Load: What Do They Mean?

If taken as directed, HIV medication can reduce the amount of HIV in the blood (also called the viral load) to a very low level. This is called viral suppression. Viral suppression helps to keep you healthy and prevents illness.

If the viral load is so low that it doesn't show up in a standard lab test, this is called having an **undetectable viral load**.

How Do You Get Your Viral Load to Undetectable and Keep It There? People living with HIV can get and keep an undetectable viral load by taking HIV medication (called antiretroviral therapy or ART) every day, exactly as prescribed. Almost everyone who takes HIV medication daily as prescribed can achieve an undetectable viral load, usually within 6 months after starting treatment. But HIV is still in the body when the viral load is suppressed, even when it is undetectable. If a person stops taking HIV medication, the viral load will quickly go back up. People who have stopped taking their medication or who are having trouble taking all doses as prescribed should talk to their health care provider as soon as possible about how to get back on track.

#### **Benefits**

There are important health benefits to having a suppressed or undetectable viral load. People living with HIV who know their status, take HIV medication daily as prescribed, and get and keep an undetectable viral load can live long and healthy lives.

**There is also a major prevention benefit**. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIV-negative partners. This is often called "treatment as prevention."

Also, if a woman living with HIV takes HIV medication as prescribed throughout pregnancy, labor, and delivery, and if HIV medicine is given to her baby for 4-6 weeks after delivery, the risk of transmission from pregnancy, labor, and delivery can be reduced to 1 percent or less.

## Talk with Your Health Care Provider

Talk with your health care provider about these benefits of HIV treatment and discuss which HIV medication is right for you. Stay in medical care so your provider can regularly monitor your viral load and make sure it remains undetectable. Also talk to your provider about ways to prevent other sexually transmitted infections (STls). Having an undetectable viral load only prevents transmission of HIV, not other STls.

Here are some tips that may help you take **every dose of your HIV medication, every day**:

- Follow your treatment plan exactly as your health care provider has prescribed. HIV medication should be taken at specific times of the day, with or without certain kinds of food. If you have questions about when and how to take your medication, talk to your health care provider or pharmacist.
- **Create a routine.** Add taking your medication to things you already do each day. For example, if your medical provider prescribes taking your medication every morning with food, make it a habit to take it at breakfast.
- **Try a weekly or monthly pill box** with compartments for each day of the week to help you remember whether or not you took your medicine that day.
- Set an alarm on your clock, watch, or phone for the time you take your HIV medication.
- **Keep a daily log or use a calendar** to keep track of the days you have taken your HIV medication.
- **Download a free app** from the Internet to your computer or on your smartphone that can help remind you when it's time to take your HIV medication. Search for "reminder apps," and you will find many choices.
- Set up automatic refills at your pharmacy. Your medicine will be ready when you need it, and you won't run out.
- Ask a family member or friend to encourage you and give you a daily phone call, text, or email to remind to take your HIV medication.
- **Continue to see your health care provider regularly.** Regular medical visits are important to monitor the amount of virus in your blood to make sure it stays undetectable, and to receive other medical support. Use these visits to

talk openly to your provider about any help you might need sticking to your treatment plan..

You can also visit HIV.gov's <u>Positive Spin</u> or CDC's <u>HIV Treatment Works</u> campaign to view stories of how people living with HIV are taking their HIV medication every day.

## What Are Some Challenges I Might Face Taking My HIV Medication Every Day?

Taking medication every day can be difficult. That is why it is important to understand some of the challenges you may face and to think through how you might address them before they happen. For example, remembering when to take your medication can be complicated. Some medication regimens involve taking several pills every day—with or without food—or before or after other medications. Making a schedule of when and how to take your medicines can be helpful. Or ask your health care provider about the availability of multiple drugs combined into one pill.

Other factors can make it difficult to take your HIV medications every day, including:

- **Problems taking medications**, such as trouble swallowing pills, can make staying on treatment challenging. Your health care provider can offer tips and ideas for addressing these problems.
- Side effects from medications, for example, nausea or diarrhea, can make a person not want to take them. Talk to your health care provider. There are medicines or other support, like nutritional counseling to make sure you are getting important nutrients, which can help with the <u>most common side effects</u>. But don't give up. Work with your health care provider to find a treatment that works for you.
- **A busy schedule.** Work or travel away from home can make it easy to forget to take pills. Planning ahead can help. Or, it may be possible to keep extra medicines at work or in your car for the times that you forget to take them at home. But make sure you talk to your health care provider—some medications are affected by extreme temperatures, and it is not always possible to keep medications at work.
- **Being sick or depressed.** How you feel mentally and physically can affect your willingness to stick to your HIV medications. Again, your health care provider is an important source of information to help with your <u>mental health</u> needs.
- **Alcohol or drug use.** If <u>substance use</u> is interfering with your ability to keep yourself healthy, it may be time to seek help to quit or better manage it.

• **Treatment fatigue.** Some people find that taking their HIV medications becomes harder over time. Every time you see your health care provider, make it a point to talk about staying adherent to your medications.

Your health care provider will help you identify barriers to keeping up with your HIV medication regimen and ways to address those barriers. Understanding issues that can make keeping up with your HIV medication regimen difficult will help you and your health care provider select the best treatment for you.

Tell your health care provider right away if you're having taking your HIV medication every day. Together you can identify the reasons why you're skipping medications and make a plan to address those reasons. Joining a peer support group of others taking HIV medication, or enlisting the support of family and friends, can also help you.

#### Content Source: <u>HIV.gov</u> Date last updated: January 09, 2019

## 4. Paying for HIV Care and Treatment

## **Paying for HIV Care**

IV care and treatment involves taking antiretroviral therapy (ART) and having regular check-ups with your healthcare provider who will monitor your health status on an ongoing basis.

These things are important because with the proper care and treatment, you can reduce your viral load, protect your health, enjoy a long and healthy life, and reduce the potential of transmitting the virus to others.

But you might have concerns about how to pay for this. There are resources that can help you pay for the care you need.

#### **Private Insurance**

**Job-Based and Individual Insurance**—Many people have private health insurance through their employer (or a family member's employer), or they have individual insurance they have purchased. Under the Affordable Care Act (ACA), most job-based and individual plans are required to offer <u>new benefits and protections</u>. For example, plans can't can drop you or deny you coverage just because you have a pre-existing health condition, like HIV. And insurers can't impose lifetime caps on your insurance benefits. However, you'll still need to pay any deductibles, copayments, and coinsurance your plan requires. Make sure you read your plan carefully so that you know what your plan will (and won't) cover.

When you leave a job, you may be able to keep your job-based health insurance for a period, usually up to 18 months. This is called <u>COBRA continuation coverage</u>. With COBRA coverage, you usually have to pay the entire monthly premium yourself, plus a small administrative fee. Your former employer no longer pays any of your insurance costs.

**The Health Insurance Marketplace**—Established under the ACA, the <u>Health Insurance</u> <u>Marketplace</u> helps uninsured people find and apply for quality, affordable health coverage. Private plans in the Marketplace are required to cover a set of <u>essential</u> <u>health benefits</u>. And, low and middle-income people may <u>qualify for lower costs</u>, based on their household size and income. To see if you can enroll in a health insurance plan or change plans, visit <u>healthcare.gov</u> or <u>find local help</u>.

#### **Federal Resources**

If you do not have private health insurance—or you need help because your insurance doesn't pay for the HIV care and treatment you need—there are Federal resources that may help you.

**Getting Help**—Figuring out which programs and services you qualify for can be confusing. But don't worry! There are case managers and benefits counselors who can help you. They know what services are available and can help you get care. Their services are free. You can find one near you by contacting a local HIV/AIDS service organization. Toll-free <u>State HIV/AIDS Hotlines</u> will help put you in touch with agencies that can determine what programs and services you may be eligible for and help you access them.

Here are Federal resources that are available:

• **Medicaid**—A state and Federal partnership, Medicaid provides coverage for people with lower incomes, older people, people with disabilities, and some families and children. It is a critical source of coverage for many people living with HIV/AIDS. States establish and administer their own Medicaid programs and determine they type, amount, duration, and scope of services within broad federal guidelines. States are required to cover certain "mandatory benefits" and can choose to provide other "optional benefits," including prescription drugs. The eligibility rules for Medicaid are different in each state, but most

states offer coverage for adults with children at some income level. And, under the ACA, states have the option, which is fully Federally funded for the first three years, to expand Medicaid eligibility to generally include people below certain income levels, including low-income childless adults who were previously not generally eligible for Medicaid. As a result, in states that opt for Medicaid expansion, people living with HIV who meet the income threshold no longer have to wait for an AIDS diagnosis in order to become eligible for Medicaid. You can apply for and enroll in Medicaid at any time. There is no limited enrollment period. If you qualify, your coverage can begin immediately. Even if your state hasn't expanded Medicaid, you should still apply for coverage to see if you qualify under your state's existing rules. <u>See if you qualify to save in</u> <u>your state</u>.

- **The Ryan White HIV/AIDS Program**—The <u>Ryan White HIV/AIDS Program</u> works with cities, states, and local community-based organizations to provide HIVrelated services to more than half a million people living with HIV/AIDS each year. The program is for those who do not have sufficient healthcare coverage or financial resources to cope with HIV disease. Ryan White fills gaps in care not covered by these other sources. The program is divided into several "parts" to meet the needs of different communities and populations, and includes support for an <u>AIDS Drug Assistance Program (ADAP)</u>. To find a Ryan White clinic near you, use the <u>HIV.gov HIV Testing and Care Services Locator</u>.
- **The Health Center Program** Health centers provide high quality preventive and primary health care services, including HIV testing and medical care, to patients regardless of their ability to pay. Some patients receive services directly at the health center itself, while others are referred to an HIV specialist in the community. Major investments in the network of community health centers over the past several years have created more opportunities for HIV care delivery. You can find a health center near you by going to the <u>HIV Testing and Care Services Locator</u>.
- **Medicare**—Medicare is health insurance for people age 65 or older, people under 65 with certain disabilities, and people of all ages with End-Stage Renal Disease. Medicare coverage for eligible individuals includes outpatient care, prescription drugs, and inpatient hospital care. To learn more about Medicare coverage and choices, visit <u>Medicare.gov</u>.
- Federal Programs for Women and Children—There are several Federal programs to help low-income women and children access health care. The <u>Children's Health Insurance Program (CHIP)</u> provides free or low-cost health insurance coverage for children up to age 19. Each state <u>has its own</u>

<u>rules</u> about who qualifies for CHIP. You can apply for and enroll a child in CHIP at any time. There is no limited enrollment period. If the child qualifies, his/her coverage can begin immediately. Visit <u>www.insurekidsnow.gov</u> to learn more and see if you are eligible for coverage or call 1-877-KIDS-NOW (1-877-543-7669). In addition, programs supported by the Maternal and Child Health Services Block Grant, authorized by <u>Title V of the Social Security Act (SSA)</u>, serve low-income women, children, and youth with limited access to health care, including children with special needs. Specifically, the Title V Maternal and Child Health program seeks to assure access to quality care, especially for those with low-incomes or limited availability of care.

- American Indian and Alaska Native Programs—The Indian Health Service (IHS) provides health care services—including <u>HIV services</u>—for members and descendents of federally-recognized American Indian and Alaska Native Tribes. For more information, go to <u>https://www.ihs.gov</u>.
- **Veterans Programs**—The <u>Veterans Administration</u> (VA) is the largest single provider of medical care to people living with HIV in the U.S., supporting over 24,000 Veterans living with HIV. If you are eligible, you may be able to receive HIV care through the Veterans Health Administration. VA offers an <u>online</u> <u>benefits website</u> where Veterans, Service Members, and their families can learn about their health care benefits.

#### **Non-Federal Resources**

Patient Assistance Programs (PAPs) are programs administered by pharmaceutical companies to offer free or reduced-cost antiretroviral (ARV) medicines to low-income people living with HIV who are uninsured or underinsured, and who do not qualify for assistance programs such as Medicaid, Medicare, or AIDS Drug Assistance Programs. Each pharmaceutical company has different eligibility criteria for qualifying for their PAP.

The U.S. Department of Health and Human Services, seven pharmaceutical companies, the National Alliance of State and Territorial AIDS Directors (NASTAD), and community stakeholders worked together to develop a <u>common patient assistance</u> <u>program application</u> (CPAPA) and <u>companion document</u> that can be used by patients and providers to access these programs.

Content Source: <u>HIV.gov</u> Date last updated: October 10, 2019

## Chapter VI. Staying in HIV Care

## C. Other Related Health Issues 1. Other Health Issues of Special Concern for People Living with HIV

#### **Do People Living with HIV Have Other Health Conditions?**

Yes. It's common for people living with HIV to have other health issues.

Some of these issues may be directly related to HIV or its treatment. Others may be completely unrelated.

These health conditions can mean more doctors' visits, lab tests, and medications to keep up with.

Taking HIV medication (called antiretroviral therapy or ART) daily as prescribed, and staying in regular medical care is the best way for people living with HIV to stay healthy.

## **Pre-Existing Conditions Related to HIV Risk**

Sometimes people living with HIV have pre-existing conditions that may have contributed to their risk for HIV infection. These conditions can sometimes complicate HIV treatment if not addressed.

Among these conditions are mental health issues, alcohol use, and drug use. The risk of HIV infection is higher among people whose lives are affected by mental health issues like depression, anxiety, or the psychological effects of bullying, sexual abuse, or physical abuse. Alcohol and drug use also increase a person's risk of exposure to HIV and other sexually transmitted diseases.

Regardless of whether they played a role in someone's risk for getting HIV, mental health and substance use disorders can make it harder for people living with HIV to take ART daily as prescribed. But behavioral health treatment and services are available. Talk openly and honestly with your health care provider about your mental health and substance use so that he or she can evaluate you and help you find the support you need. Use SAMHSA's Behavioral Health Treatment Locator to find mental health and substance abuse treatment facilities near you.

# **Common Coinfections**

Coinfection is when a person has two or more infections at the same time. There are some common coinfections that affect people living with HIV. For example:

- **Hepatitis B and Hepatitis C**—Hepatitis B and C are contagious liver diseases. Like HIV, hepatitis B virus (HBV) and hepatitis C virus (HCV) can be transmitted sexually or by injection drug use. So about one-third of people living with HIV in the United States are coinfected with either HBV or HCV. If left untreated, they can lead to liver disease, liver cancer, and liver failure. Hepatitis B can be prevented with a vaccine. There is no cure for hepatitis B, but treatment can delay or limit liver damage. There is no vaccine for hepatitis C, but treatment cures up to 90 percent of people who take it in 12-24 weeks. Everyone living with HIV should be tested for hepatitis B and C. Learn more about hepatitis B and C and people living with HIV.
- **Tuberculosis**—Tuberculosis (TB) is a disease caused by germs spread through the air from a person with untreated TB disease. TB usually affects the lungs, but it can affect other parts of the body. It can cause serious health problems if left untreated. Worldwide, TB is one of the leading causes of death among people living with HIV. That's why it is important for people living with HIV to be tested for TB and for those who test positive to begin treatment. Learn about HIV and TB coinfection.
- **Opportunistic infections**—Opportunistic infections (OIs) are infections that occur more frequently or are more severe in people with weakened immune systems, such as people with HIV. People are at greatest risk for OIs when their CD4 count falls below 200. When a person with HIV gets certain OIs or specific cancers, they will get diagnosed with AIDS (also known as HIV Stage 3), the most serious stage of HIV infection. Taking HIV medication daily as prescribed, staying in regular medical care, and getting your lab tests done are key to staying healthy and preventing these infections. Learn more about how opportunistic infections affect people living with HIV.

# **Other Health Conditions Associated with HIV**

Thanks to improvements in HIV treatment, people living with HIV are living longer than ever. But even when HIV is well controlled with medication, it causes chronic inflammation. Over time, that takes a toll on the body, putting people living with HIV at greater risk for health conditions such as cardiovascular disease, kidney disease, diabetes, bone disease, liver disease, cognitive disorders, and some types of cancer. Your health care provider will work with you, or may refer you to a specialist, to treat any of these conditions you may develop.

Some people also experience side effects from HIV medicines that can continue for a long time. See your health care provider regularly and discuss any side effects you experience. Never cut down, skip, or stop taking your HIV medications unless your health care provider tells you to. Your provider will work with you to develop a plan to manage the side effects, or may recommend that you change medication.

Be sure to take care of your emotional wellness, eat a healthy diet, exercise, and quit smoking. These all play an important role in living healthy with HIV.

Content Source: HIV.gov Date last updated: May 01, 2019

# 2. Alcohol and Drug Use

Alcohol and drug use can be harmful to your health and get out of hand for some people. Modest use of alcohol can help your heart health in some circumstances, but it can also lead to long-term effects that are harmful and reduce your ability to fight off HIV. Different drugs have different effects on the body, and they can affect your judgement, mental health, and physical health differently. The use of illegal drugs presents multiple risks to the health of people living with HIV including harmful effects on the body and the risks associated with injection drug use, and risks associated with sexual transmission of HIV.

# How Can Alcohol, Drug Use, and HIV Affect Your Health?

Alcohol and drug use, abuse, and dependence may damage your body and brain, and drug overdoses can cause death. This damage to your body and brain can negatively affect your health and well-being in many ways. These are just some examples.

- Physical effects:
  - Drinking too much can damage your brain, liver, and immune system.
     Chronic drinkers with HIV may be at greater risk for disease progression than those who drink very little or not at all (read more).
  - Methamphetamines can lead to brain, liver, and kidney damage, impaired blood circulation, significant weight loss, and tooth decay.

- Drugs like cocaine and heroin can seriously damage your respiratory and circulatory systems.
- Methamphetamines and cocaine can negatively affect your immune system, making it easier for your body to get an infection.
- Some substances interfere with HIV medicines that are part of an overall treatment plan.
- Other effects:
  - The after-effects of a drug or alcohol "high" can create feelings of depression, exhaustion, pain, and/or irritability.
  - Getting high may cause you to forget to take your HIV medicines or forget to make and keep doctor and clinic appointments.
  - Using drugs can make it hard for you to maintain your house, job, relationships, and social supports—all of which are important for your well-being.
  - If you inject drugs, you may be at increased risk for transmitting or getting HIV. You may also be at risk for other infections that are transmitted by blood such as hepatitis B and hepatitis C. Learn more about reducing the risk from injecting drugs. Using drugs can make you more prone to risky practices, such as sharing needles or not using condoms. This increases the chance that you could transmit HIV or get a sexually transmitted disease (STD) that could make your infection worse.

# How Can You Find Treatment or Support Programs?

Choosing to stop using drugs or alcohol is not easy, but it can be done. Quitting will improve your health, well-being, and relationships with others.

- Different types of substance use require different types of treatment. Based on your level of dependence, you may need medical treatment and/or psychological therapy to help you quit. Talk with your health care provider to explore treatment options that are specific to your type of substance use.
- Peer support and faith-based recovery groups may also help you manage substance use and dependence.

Support is available. Many organizations provide hotlines and guidance on substance abuse treatment options:

• Use the Substance Abuse & Mental Health Services Administration (SAMHSA) Substance Abuse Treatment Facility Locator to find alcohol and substance abuse treatment facilities and programs near you. Or call SAMHSA's national helpline: 1-800-662-HELP (4357).

• Find treatment options for opioid abuse by specific drug or by state. Use SAMHSA's Opioid Treatment Program Directory and Buprenorphine Physician and Treatment Program Locator for information you can use.

CDC offers more information on substance abuse and treatment.

**Content Source:** CDC's HIV Basics **Date last updated:** May 15, 2017

# 3. Hepatitis B & C

# HIV and Hepatitis B and Hepatitis C Coinfection

About 1 in 10 people living with HIV are coinfected with hepatitis B virus (HBV), and about 1 in 4 people are coinfected with hepatitis C virus (HCV).

Hepatitis B and C are liver infections caused by a virus. Because these infections can be spread in the same ways as HIV, people with HIV in the United States are often also affected by chronic viral hepatitis.

Viral hepatitis progresses faster and causes more liver-related health problems among people with HIV than among those who do not have HIV. Liver disease, much of which is related to HBV or HCV, is a major cause of non-AIDS-related deaths among people living with HIV.

Given the risks of hepatitis B or hepatitis C coinfection to the health of people living with HIV, it is important to understand these risks, take steps to prevent infection, know your status, and, if necessary, get medical care from someone who is experienced in treating people who are coinfected with HIV and HBV, or HIV and HCV.

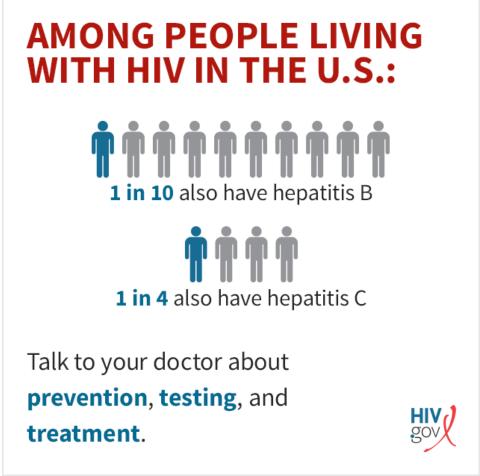
# How Are Hepatitis B and C Spread from Person to Person?

Like HIV, the hepatitis B and C viruses spread:

• By sharing needles, syringes, and other injection equipment.

- Sexually: Both viruses can also be transmitted sexually, but HBV is much more likely than HCV to be transmitted sexually. Sexual transmission of HCV is most likely to happen among gay and bisexual men who are living with HIV.
- From mother to child: Pregnant women can pass these infections to their infants. HIV-HCV coinfection increases the risk of passing on hepatitis C to the baby.

Is Hepatitis Testing Recommended for People with HIV?



Yes. Everyone living with HIV should be tested for HBV and HCV when they are first diagnosed with HIV and begin treatment. People living with HIV who have ongoing risk factors for getting hepatitis B or C should be tested annually.

# How Can You Prevent Hepatitis B and C?

Hepatitis B: Vaccination is the best way to prevent all of the ways that hepatitis B is transmitted. People with HIV who do not have active HBV infection should be vaccinated against it.

Hepatitis C: No vaccine exists for HCV. The best way to prevent hepatitis C infection is to never inject drugs or to stop injecting drugs by getting into and staying in drug treatment. If you continue injecting drugs, always use new, sterile needles or syringes, and never reuse or share needles or syringes, water, or other drug preparation equipment.

#### **Treatment for HIV-Hepatitis Coinfection**

HIV-HBV and HIV-HCV coinfections can be effectively treated in most people. But treatment can be complex, and people with coinfection should look for health care providers with expertise in the management of both HIV infection and viral hepatitis.

Hepatitis B: For hepatitis B, treatment can delay or limit liver damage by suppressing the virus. Like treatment for HIV, hepatitis B treatment may need to be taken for the rest of your life.

Hepatitis C: New treatments for hepatitis C have been approved in recent years. These direct-acting treatments are much better than the previously available treatment because they have few side effects and do not need to be injected. These treatments for HCV infection cure more than 90% of people, including those living with HIV, in 12-24 weeks.

**Content Source:** HIV.gov **Date last updated:** April 30, 2019

# 4. Immunizations Recommended for People Living With HIV

#### What Are Immunizations?

Immunizations (also called "vaccines") protect people from diseases such as chicken pox, flu, and polio. Vaccines are given by needle injection (a shot), by mouth, or sprayed into the nose.

Most vaccines are designed to prevent a person from ever having a disease or so that a person will only have a mild case of the disease. When a person gets a vaccine, his or her body responds by mounting an immune system response to defend the body against the infection.

Since HIV can make it difficult for your immune system to fight infections, people living with HIV could benefit greatly from vaccines against preventable infections.

Also, vaccines don't just protect individuals from disease. They also protect communities. When most people in a community get immunized against a disease, there is little chance of a disease outbreak.

# Which Vaccines are Recommended for People Living with HIV?

The following vaccines are recommended for people living with HIV:

- Hepatitis B
- Influenza (flu)
- Pneumococcal (pneumonia)
- Tetanus, diphtheria, and pertussis (whooping cough). A single vaccine called Tdap protects adolescents and adults against the three diseases. Every 10 years, a repeat vaccine against tetanus and diphtheria (called Td) is recommended.
- Human papillomavirus (HPV) (for those up to age 26)

Additional vaccines may be recommended based on an HIV-infected person's age, previous vaccinations, risk factors for a particular disease, or certain HIV-related factors. Talk to your health care provider about which vaccines are recommended for you. For more details, read this information from the Centers for Disease Control and Prevention (CDC): HIV Infection and Adult Vaccination.

# Are All Types of Vaccines Safe for People Living with HIV?

There are two basic types of vaccines:

- Live, attenuated vaccines are vaccines that contain a weakened but live form of a disease-causing microbe. Although the weakened microbe cannot cause the disease (or can cause only mild disease), the vaccine can still trigger an immune response.
- Inactivated vaccines are vaccines that are made from dead microbes. There is no chance that an inactivated vaccine can cause the disease it was designed to prevent.

In general, to be safe, **people with HIV should get inactivated vaccines** to avoid even the remote chance of getting a disease from a live, attenuated vaccine. However, for some diseases, only live, attenuated vaccines are available. In this case, the protection offered by the live vaccine may outweigh the risks. Vaccines against chicken pox and shingles are examples of live, attenuated vaccines that, in certain situations, may be recommended for people with HIV. Talk to your health care provider about what is recommended for you.

# Can HIV Affect How Well a Vaccine Works?

Yes. HIV can weaken your body's immune response to a vaccine, making the vaccine less effective. In general, vaccines work best when your CD4 count is above 200 copies/mm<sup>3</sup>.

Also, by stimulating your immune system, vaccines may cause your HIV viral load to increase temporarily.

Because HIV medicines strengthen the immune system and reduce HIV viral load, people living with HIV may want to start antiretroviral therapy (ART) before getting vaccinated whenever possible. In some situations, however, immunizations should be given even if ART has not been started. For example, it's important for people with HIV to get vaccinated against the flu at the time of year when the risk of flu is greatest. Talk to your health care provider about what is recommended for you.

# **Do Vaccines Cause Side Effects?**

Any vaccine can cause side effects. Side effects from vaccines are generally minor (for example, soreness at the location of an injection or a low-grade fever) and go away within a few days.

Severe reactions to vaccines are rare. Before getting a vaccine, talk to your health care provider about the benefits and risks of the vaccine and possible side effects. Learn about vaccine safety and possible side effects.

# What About Travel and Vaccines?

You should be up to date on routine vaccinations, no matter where you are going. If you are planning a trip outside the United States, you may need immunizations against diseases that are present in other parts of the world, such as cholera or yellow fever.

If you have HIV, talk to your health care provider about any vaccines you may need before you travel. He or she will know which vaccines are safe for you. Keep in mind:

- If a required immunization is available only as a live, attenuated vaccine, ask your health care provider if the potential benefits are greater than the potential risks. If so, your provider may be willing to give you a letter excusing you from getting the vaccine (although not all countries accept waiver letters.)
- If your CD4 count is less than 200 copies/mm<sup>3</sup>, your health care provider may recommend that you delay travel to give your HIV medicines time to strengthen your immune system.

#### Is There a Vaccine Against HIV?

No. There is currently no vaccine that has been approved by the FDA to prevent HIV infection or treat those who have it. However, scientists are working to develop one. Learn about HIV vaccine research.

Content Source: AIDS Info Date last updated: May 15, 2017

# 5. Mental Health

# Mental Health and HIV

Almost every person faces mental health challenges at some point. Major stresses like the death of a loved one, divorce, loss of a job, or moving—can have a major impact on mental health. Having a serious illness, like HIV, can be another source of major stress. You may find that a diagnosis of HIV challenges your sense of well-being or complicates existing mental health conditions. HIV and some opportunistic infections can also affect your nervous system and can lead to changes in your behavior.

Good mental health will help you live your life to the fullest and is essential to successfully treating HIV. To help manage your mental health, it is important to know when, how, and where to get help. Many mental health conditions are treatable and many people with mental health conditions recover completely.

One of the most common mental health conditions that people living with HIV face is depression. Depression can range from mild to severe, and the symptoms of depression can affect your day-to-day life. Both HIV-related medical conditions and HIV medications can contribute to depression.

Symptoms can include:

- Feeling sad or anxious often or all the time
- Not wanting to do activities that used to be fun
- Feeling irritable, easily frustrated, or restless
- Having trouble falling asleep or staying asleep
- Waking up too early or sleeping too much
- Eating more or less than usual or having no appetite
- Experiencing aches, pains, headaches, or stomach problems that do not improve with treatment
- Having trouble concentrating, remembering details, or making decisions
- Feeling tired, even after sleeping well
- Feeling guilty, worthless, or helpless
- Thinking about suicide or hurting yourself

Other mental health conditions include anxiety disorders, mood disorders, and personality disorders. For a good description of specific mental health conditions and their symptoms, visit mentalhealth.gov.

**Getting help in a crisis.** At times, the problems of life can take a toll on people. Some might feel trapped, hopeless, or might wonder what they have to live for. If you are having thoughts like these or are thinking about hurting or killing yourself, know that you are not alone and that things can change. SAMHSA's Suicide Prevention Lifeline provides 24/7, free and confidential support for people in distress. Get information online or call:(800) 273-TALK (8255). You can also:

- Call your HIV health care provider.
- Get help from another health care provider.
- Reach out to a close friend or loved one.
- Contact a minister, spiritual leader, or someone else in your faith community.

# Talk to Your HIV Health Care Provider

Talk to your HIV health care provider if you are experiencing any of the symptoms above. Your provider may ask you some questions to assess how you are feeling and may prescribe medications to help with depression or anxiety or refer you to a mental health specialist.

If you are taking antiretroviral therapy (ART) or plan to take ART, consider the following:

- Sometimes ART can relieve your anxiety because knowing you are taking care of yourself can give you a sense of securing.
- However, some antiretroviral medications may cause symptoms of depression, anxiety, and sleep disturbance, and may make some mental health issues worse. Talk to your health care provider to better understand how your HIV treatment might affect your mental health and if anything can be done to address the side effects.
- Also, some medicines for mental health conditions or mood disorders can interact with ART.

Communicate openly and honestly with your health care provider about your mental health so that he or she can help you find the support you need. Discuss any changes in the way you are thinking, or how you are feeling about yourself and life in general.

# **Mental Health Providers and Programs**

Because mental health conditions are common, many outlets can help you maintain good mental health. If you are having symptoms of depression or another mental health condition, talk to your health care provider, social worker, or case manager. These people can refer you to a mental health provider who can give you the care you need.

Types of mental health providers include:

- Psychiatrists: Medically trained physicians who treat mental health problems with various therapies, like talk therapy, and by prescribing medicine.
- Psychologists: Trained professionals who help people cope with life challenges and mental health problems with therapies, like talk therapy, but usually cannot prescribe medicines.
- Therapists: Mental health or marriage and family counselors who help people cope with life issues and mental health problems.

You may also choose to join a support group. Support groups include:

- Mental health support groups: An organized group of peers who meet in a safe and supportive environment to provide mental health support to members of the group.
- HIV support groups: An organized group of peers living with HIV who meet in a safe and supportive environment to provide support to other people living with HIV.

Work with a trained mental health professional to learn about treatment options such as therapy and/or medicine. You and your provider can develop a plan that will help you regain and maintain good mental health.

Other ways to help improve mental health and well-being include:

- Exercise: Regular exercise may help improve symptoms of depression and decrease stress. When you exercise, your brain releases chemicals called endorphins. These chemicals help improve your mood.
- Meditation: Recent studies suggest that mindfulness meditation can help ease depression, anxiety, and stress.

You may find it helpful to create an action plan for your mental well-being. SAMHSA offers a free self-help guide you can use to create and maintain a wellness plan for yourself.

# **Find Mental Health Services**

Many organizations have websites and telephone hotlines that can help you find treatment for mental health conditions.

• Substance Abuse & Mental Health Services Administration (SAMHSA)'s Find Help website provides a list of organizations and contact numbers that can help you find mental health treatment and support in your local area.

Content Source: HIV.gov Date last updated: May 08, 2018

# 6. Opportunistic Infections

# What Are Opportunistic Infections?

Opportunistic infections (OIs) are infections that occur more frequently and are more severe in people with weakened immune systems, including people with HIV.

Many OIs are considered AIDS-defining conditions. That means if a person with HIV has one of these conditions, they are diagnosed with AIDS, the most serious stage of HIV infection.

When a person with HIV gets certain infections (called opportunistic infections, or OIs) or specific cancers, they will get diagnosed with AIDS (also known as HIV Stage 3), the

most serious stage of HIV infection. AIDS is also diagnosed if a person's CD4 cells falls below a certain level.

What are Some of the Most Common Opportunistic Infections?

Some of the most common OIs in people living with HIV in the U.S. are:

- Herpes simplex virus 1 (HSV-1) infection—a viral infection that can cause sores on the lips and mouth
- Salmonella infection—a bacterial infection that affects the intestines
- **Candidiasis (thrush)**—a fungal infection of the mouth, bronchi, trachea, lungs, esophagus, or vagina
- **Toxoplasmosis**—a parasitic infection that can affect the brain

A more detailed list found at the CDC

https://www.cdc.gov/hiv/basics/livingwithhiv/opportunisticinfections.html includes:

Candidiasis of bronchi, trachea, esophagus, or lungs	This illness is caused by infection with a common (and usually harmless) type of fungus called <i>Candida</i> . Candidiasis, or infection with <i>Candida</i> , can affect the skin, nails, and mucous membranes throughout the body. Persons with HIV infection often have trouble with <i>Candida</i> , especially in the mouth and vagina. However, candidiasis is only considered an OI when it infects the esophagus (swallowing tube) or lower respiratory tract, such as the trachea and bronchi (breathing tube), or deeper lung tissue.
Invasive cervical cancer	This is a cancer that starts within the cervix, which is the lower part of the uterus at the top of the vagina, and then spreads (becomes invasive) to other parts of the body. This cancer can be prevented by having your care provider perform regular examinations of the cervix
Coccidioidomycosis	This illness is caused by the fungus <i>Coccidioides</i> <i>immitis</i> . It most commonly acquired by inhaling fungal spores, which can lead to a pneumonia that

	is sometimes called desert fever, San Joaquin Valley fever, or valley fever. The disease is especially common in hot, dry regions of the southwestern United States, Central America, and South America.
Cryptococcosis	This illness is caused by infection with the fungus <i>Cryptococcus neoformans</i> . The fungus typically enters the body through the lungs and can cause pneumonia. It can also spread to the brain, causing swelling of the brain. It can infect any part of the body, but (after the brain and lungs) infections of skin, bones, or urinary tract are most common.
Cryptosporidiosis, chronic intestinal (greater than one month's duration)	This diarrheal disease is caused by the protozoan parasite <i>Cryptosporidium</i> . Symptoms include abdominal cramps and severe, chronic, watery diarrhea.
Cytomegalovirus diseases (particularly retinitis) (CMV)	This virus can infect multiple parts of the body and cause pneumonia, gastroenteritis (especially abdominal pain caused by infection of the colon), encephalitis (infection) of the brain, and sight- threatening retinitis (infection of the retina at the back of eye). People with CMV retinitis have difficulty with vision that worsens over? time. CMV retinitis is a medical emergency because it can cause blindness if not treated promptly.
Encephalopathy, HIV-related	This brain disorder is a result of HIV infection. It can occur as part of acute HIV infection or can result from chronic HIV infection. Its exact cause is unknown but it is thought to be related to infection of the brain with HIV and the resulting inflammation.
Herpes simplex (HSV): chronic ulcer(s) (greater than one month's duration); or bronchitis, pneumonitis, or esophagitis	Herpes simplex virus (HSV) is a very common virus that for most people never causes any major problems. HSV is usually acquired sexually or from an infected mother during birth. In most people with healthy immune systems, HSV is usually latent

	(inactive). However, stress, trauma, other infections, or suppression of the immune system, (such as by HIV), can reactivate the latent virus and symptoms can return. HSV can cause painful cold sores (sometime called fever blisters) in or around the mouth, or painful ulcers on or around the genitals or anus. In people with severely damaged immune systems, HSV can also cause infection of the bronchus (breathing tube), pneumonia (infection of the lungs), and esophagitis (infection of the esophagus, or swallowing tube).
Histoplasmosis	This illness is caused by the fungus <i>Histoplasma</i> <i>capsulatum</i> . <i>Histoplasma</i> most often infects the lungs and produces symptoms that are similar to those of influenza or pneumonia. People with severely damaged immune systems can get a very serious form of the disease called progressive disseminated histoplasmosis. This form of histoplasmosis can last a long time and involves organs other than the lungs.
Isosporiasis, chronic intestinal (greater than one month's duration)	This infection is caused by the parasite <i>Isospora belli</i> , which can enter the body through contaminated food or water. Symptoms include diarrhea, fever, headache, abdominal pain, vomiting, and weight loss.
Kaposi's sarcoma (KS)	This cancer, also known as KS, is caused by a virus called Kaposi's sarcoma herpesvirus (KSHV) or human herpesvirus 8 (HHV-8). KS causes small blood vessels, called capillaries, to grow abnormally. Because capillaries are located throughout the body, KS can occur anywhere. KS appears as firm pink or purple spots on the skin that can be raised or flat. KS can be life-threatening when it affects organs inside the body, such the lung, lymph nodes, or intestines.

Lymphoma, multiple forms	Lymphoma refers to cancer of the lymph nodes and other lymphoid tissues in the body. There are many different kinds of lymphomas. Some types, such as non-Hodgkin lymphoma and Hodgkin lymphoma, are associated with HIV infection.
Tuberculosis (TB)	Tuberculosis (TB) infection is caused by the bacteria <i>Mycobacterium tuberculosis</i> . TB can be spread through the air when a person with active TB coughs, sneezes, or speaks. Breathing in the bacteria can lead to infection in the lungs. Symptoms of TB in the lungs include cough, tiredness, weight loss, fever, and night sweats. Although the disease usually occurs in the lungs, it may also affect other parts of the body, most often the larynx, lymph nodes, brain, kidneys, or bones.
Mycobacterium avium complex (MAC) or Mycobacterium kansasii, disseminated or extrapulmonary. Other Mycobacterium, disseminated or extrapulmonary.	MAC is caused by infection with different types of mycobacterium: <i>Mycobacterium</i> <i>avium</i> , <i>Mycobacterium intracellulare</i> , or <i>Mycobacterium kansasii</i> . These mycobacteria live in our environment, including in soil and dust particles. They rarely cause problems for persons with healthy immune systems. In people with severely damaged immune systems, infections with these bacteria spread throughout the body and can be life-threatening.
<i>Pneumocystis carinii</i> pneumonia (PCP)	This lung infection, also called PCP, is caused by a fungus, which used to be called <i>Pneumocystis carinii</i> , but now is named <i>Pneumocystis jirovecii</i> . PCP occurs in people with weakened immune systems, including people with HIV. The first signs of infection are difficulty breathing, high fever, and dry cough.
Pneumonia, recurrent	Pneumonia is an infection in one or both of the lungs. Many germs, including bacteria, viruses, and fungi can cause pneumonia, with symptoms such as a cough (with mucous), fever, chills, and trouble

	<ul> <li>breathing. In people with immune systems severely damaged by HIV, one of the most common and life-threatening causes of pneumonia is infection with the bacteria <i>Streptococcus pneumoniae</i>, also called <i>Pneumococcus</i>. There are now effective vaccines that can prevent infection with <i>Streptococcus pneumoniae</i> and all persons with HIV infection should be vaccinated.</li> </ul>
Progressive multifocal leukoencephalopathy	This rare brain and spinal cord disease is caused by the JC (John Cunningham) virus. It is seen almost exclusively in persons whose immune systems have been severely damaged by HIV. Symptoms may include loss of muscle control, paralysis, blindness, speech problems, and an altered mental state. This disease often progresses rapidly and may be fatal.
<i>Salmonella</i> septicemia, recurrent	Salmonella are a kind of bacteria that typically enter the body through ingestion of contaminated food or water. Infection with salmonella (called salmonellosis) can affect anyone and usually causes a self-limited illness with nausea, vomiting, and diarrhea. Salmonella septicemia is a severe form of infection in which the bacteria circulate through the whole body and exceeds the immune system's ability to control it.
Toxoplasmosis of brain	This infection, often called toxo, is caused by the parasite <i>Toxoplasma gondii</i> . The parasite is carried by warm-blooded animals including cats, rodents, and birds and is excreted by these animals in their feces. Humans can become infected with it by inhaling dust or eating food contaminated with the parasite. <i>Toxoplasma</i> can also occur in commercial meats, especially red meats and pork, but rarely poultry. Infection with toxo can occur in the lungs, retina of the eye, heart, pancreas, liver, colon, testes, and brain. Although cats can transmit toxoplasmosis, litter boxes can be changed safely by

	wearing gloves and washing hands thoroughly with soap and water afterwards. All raw red meats that have not been frozen for at least 24 hours should be cooked through to an internal temperature of at least 150°F.
Wasting syndrome due to HIV	Wasting is defined as the involuntary loss of more than 10% of one's body weight while having experienced diarrhea or weakness and fever for more than 30 days. Wasting refers to the loss of muscle mass, although part of the weight loss may also be due to loss of fat.

# What Causes Opportunistic Infections?

OIs are caused by a variety of germs (viruses, bacteria, fungi, and parasites). These germs spread in different ways, such as in the air, in body fluids, or in contaminated food or water. They can cause health problems when a person's immune system is weakened by HIV disease.

# Who Is at Risk for Opportunistic Infections?

People living with HIV are at greatest risk for OIs when their CD4 count falls below 200. However, some OIs can occur when a person's CD4 count is below 500. That's because weakened immune system makes it harder for the body to fight off HIV-related OIs.

# Are Opportunistic Infections Common in People with HIV?

OIs are less common now than in the early days of HIV and AIDS when there was no treatment. Today's <u>HIV medicines</u> (called antiretroviral therapy or ART) reduce the amount of HIV in a person's body and keep the immune system stronger and better able to fight off infections.

However, some people with HIV still develop OIs for reasons such as:

- they do not know they have HIV and so they are not on treatment
- they know they have HIV but are not taking ART
- they were living with HIV for a long time before they were diagnosed and so have a weakened immune system

• they are taking ART, but their drug combination is not working as expected and is not keeping their HIV levels low enough for their immune system to fight off infections



# How Can You Prevent Getting Opportunistic Infections?

The best way to prevent OIs is to <u>take HIV medication daily as prescribed</u> so that you can get and keep an undetectable viral load and keep your immune system strong.

It is also important to stay in HIV medical care and get <u>lab tests</u> done. This will allow you and your health care provider to know when you might be at risk for OIs and discuss ways to prevent them.

Some of the ways people living with HIV can reduce their risk of getting an OI include:

- avoiding exposure to contaminated water and food
- taking medicines to prevent certain OIs
- getting vaccinated against some preventable infections
- traveling safely

**Can Opportunistic Infections Be Treated?** 

If you develop an OI, there are treatments available such as <u>antiviral</u>, <u>antibiotic</u>, and <u>antifungal</u> drugs. The type of medicine used depends on the OI.

Once an OI is successfully treated, a person may continue to use the same medicine or an additional medicine to prevent the OI from coming back. Having an OI may be a very serious medical situation and its treatment can be challenging.

For more information about specific OIs, visit CDC's Opportunistic Infections.

Content Source: <u>HIV.gov</u> Date last updated: July 16, 2019

# 7. Sexually Transmitted Diseases

#### What Do You Need to Know About STDs?

Living healthy with HIV includes preventing other sexually transmitted diseases (STDs). An STD is an infection that's passed from person to person through sexual contact. HIV is an example of an STD.

Other types of STDs include:

- Chlamydia,
- Genital herpes,
- Gonorrhea,
- Hepatitis B and C,
- Human papilloma virus (HPV), and
- Syphilis.

The only way to avoid getting other STDs is to not have vaginal, anal, or oral sex. If you are sexually active, you can do the following things to lower your chances of getting other STDs:

- Choose less risky sexual behaviors
- Use condoms consistently and correctly
- Reduce the number of people with whom you have sex
- Limit or eliminate drug and alcohol use before and during sex

• Have an honest and open talk with your health care provider and ask how frequently you should be tested for STDs.

For people living with HIV, it can be harder to treat STDs. STDs increase your viral load in your genital fluids, and some types of STDs can lower your CD4 count. Because HIV weakens the CD4 cells in the immune system, your body has a harder time fighting off STDs. This also means that if you are living with HIV and also have an STD, you may be able to transmit HIV to your partner(s) even if your viral load is undetectable. In fact, people living HIV who are also infected with another STD are 3 to 5 times as likely as others living with HIV to spread HIV through sexual contact.

Also, some sexually transmitted diseases affect women living with HIV differently than they affect women who do not have HIV. Learn more about these differences.

**It's important for people with HIV to get tested and treated for other STDs.** Being tested and treated for STDs helps you maintain good health and avoid transmitting an STD unknowingly. If you have HIV and are sexually active, get tested at least once a year.

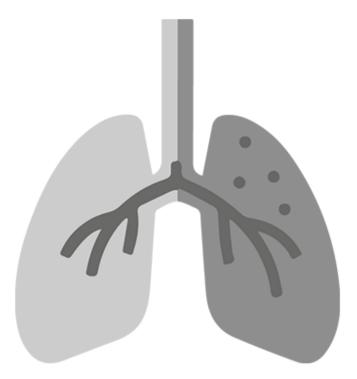
Encourage your partner(s) to do the same. You or your partner(s) can have an STD without having symptoms. You and your partner should determine what sexual behaviors and prevention practices are going to be used in your relationship—and outside of it if you are not exclusive. **The goal of this communication is to keep you BOTH healthy and free from new infections.** 

Your health care provider can offer you the best care if you discuss your sexual history openly.

# 8. Smoking

# How Does Smoking Affect People Living with HIV?

Smoking is dangerous for everyone—it is the leading cause of preventable death in the U.S. But the risks of serious health consequences are much higher for people living with HIV, who smoke at a rate 2 to 3 times greater than the general population.



# The risks of serious **SMOKING-RELATED** health **CONSEQUENCES** are much **HIGHER** for those living with **HIV**

Smoking has many negative health effects on people living with HIV. For example, smokers living with HIV are more likely than nonsmokers with HIV to:

- 1. Develop lung cancer, head and neck cancers, cervical and anal cancers, and other cancers;
- 2. Develop bacterial pneumonia; *pneumocystis* pneumonia, a dangerous lung infection; COPD, and heart disease;
- 3. Develop conditions that affect the mouth, such as oral candidiasis (thrush) and oral hairy leukoplakia;
- 4. Have a poorer response to antiretroviral therapy (ART);

- 5. Have a greater chance of developing a <u>life-threatening illness</u> that leads to an AIDS diagnosis, and
- 6. Have a shorter lifespan than people living with HIV who do not smoke.

In fact, <u>one study</u> looking at the risk of lung cancer death due to smoking for a person living with HIV found that smokers living with HIV who are adherent to antiretroviral therapy (ART) are more six to 13 times more likely to die of lung cancer than from AIDS-related causes.

# What Are the Health Benefits of Quitting?

Quitting smoking has major and immediate health benefits for tobacco users, including people living with HIV. These benefits include:

- 1. Lowering your risk of lung cancer and many other types of cancer
- 2. Reducing your risk of heart disease, stroke, and COPD,
- 3. Reducing HIV-related symptoms,
- 4. Having an improved quality of life, and
- 5. Reducing your risk for infertility if you are a woman of childbearing age. Women who stop smoking during pregnancy also reduce their risk of having a low birth weight baby.

#### You are never too old to quit.

# Find Help to Quit Smoking

Talk with your health care provider about programs and products that can help you quit smoking.

You also can learn about the benefits of quitting smoking and get tips for quitting from CDC's national tobacco education campaign—<u>Tips From Former Smokers (Tips</u>). The Tips campaign profiles real people—not actors—who are living with serious long-term health effects from smoking and secondhand smoke exposure. You can also <u>view a</u> <u>story and tips</u> from a person living with HIV who quit smoking.

Visit <u>betobaccofree.hhs.gov</u> or call the Smoking Quitline: 877-44U-QUIT (877-448-7848) for more information on the many health benefits of quitting smoking. For help from your state quitline, call 1-800-QUIT-NOW (1-800-784-8669).

**Content Source:** <u>HIV.gov</u> **Date last updated:** November 08, 2018

# 9. Women's Health Issues

# How Does HIV Affect Women Differently?

HIV may cause some health problems that are unique to women, such as:

- Gynecological health issues
- Increased risk of cervical cancer
- Increased risk of heart disease
- HIV medicine side effects and drug interactions
- Aging-related issues

Pregnancy and birth control also require careful management with a health care provider.

The good news is that women who take HIV medicine (called antiretroviral therapy or ART) daily as prescribed and get and keep an undetectable viral load can stay healthy and have effectively no risk of transmitting HIV to an HIV-negative partner through sex.

# **Gy**necological Health Issues and HIV

Gynecological problems are common among women living with HIV. Some of the issues women may experience are:

- **Problems related to sexually transmitted diseases (STDs)**—Some STDS, like <u>genital herpes</u>, <u>pelvic inflammatory disease</u> (PID), and <u>chancroid</u> can happen more often and be more severe and/or harder to treat in women living with HIV than in HIV-negative women. STD screening and treatment is important for the health of a woman living with HIV and because having HIV and <u>other STDs</u> may increase the risk of HIV transmission to sexual partners.
- **Vaginal yeast infections**—In women living with HIV, <u>vaginal yeast</u> <u>infections</u> can occur more frequently and be harder to treat. Recurring vaginal yeast infections (those that happen at least four times a year) can happen more often in women with advanced HIV or AIDS.
- **Bacterial vaginosis (BV)**—BV is a condition caused by changes in the amount of certain types of bacteria found in the vagina. <u>BV</u> is more common in women living with HIV and may be harder to treat.
- **Menstrual cycle problems**—Women living with HIV may experience missed periods, lighter or heavier bleeding, or more severe <u>premenstrual syndrome</u>.

Treatment is available for these health conditions. Talk to your health care team about treatment options that are right for you.

# **Cervical Cancer and HIV**

Women with HIV have a higher risk of cervical cancer. It is important that they be screened regularly for this disease.

Cervical cancer is cancer that starts in the cervix, the lower, narrow part of the uterus (the womb). It is almost always caused by <u>human papillomavirus</u> (HPV) infection.

The types of HPV that cause cervical cancer are more common in women with HIV. For this reason, women with HIV need to get regular <u>Pap tests</u> to help find changing cervical cells before they turn into cancer. Talk to your health care provider about the Pap test schedule that is right for you. In addition, the HPV vaccine is recommended for women (and men) with HIV infection through age 26.

Cervical cancer is an AIDS-defining cancer. That means that a diagnosis of cervical cancer marks the point at which a person's HIV infection has progressed to AIDS.

#### **HIV Medicine Side Effects and Drug Interactions**

HIV medicine works as well for women as it does for men. However, some medicines can cause different side effects in women than men. For example:

- **Nevirapine side effects**—Studies have linked the HIV medicine <u>nevirapine</u> (also called Viramune or NVP) to a higher risk of rashes and liver problems for women with higher CD4 counts.
- **Ritonavir side effects**—The HIV medicine <u>ritonavir</u> (also called Norvir or RTV) may cause more nausea and vomiting in women. It is sometimes prescribed to help other HIV medicines work better.

HIV medicines can also put women at higher risk than men of getting fat buildup throughout their bodies or of having pancreas problems.

In addition, HIV medicines can interact with other drugs, which can harm you or make your HIV medicines less effective. These include:

- Prescribed medications
- Over-the-counter medicines
- Recreational drugs and alcohol

• Herbal remedies

If you are taking HIV medicines and have problems with any <u>side effects</u> or questions about drug interactions, talk to your health care provider or pharmacist to find solutions that work for you. Do NOT cut down on, skip, or stop taking your HIV medicines unless your provider tells you to.

# Women's Aging and HIV

Thanks to effective HIV treatment, women with HIV are living longer lives. That also means that as they age, they face the same health problems that many other older women do, such as heart disease, diabetes, high blood pressure, arthritis, and some cancers.

Women with HIV also may face also other health concerns as they age. These include:

- **Menopause**—Women with HIV may enter <u>menopause</u> younger or have more severe hot flashes than women who do not have HIV. Researchers also think the drop in the female hormone estrogen after menopause may affect women's CD4 counts.
- **Osteoporosis**—Osteoporosis is a disease that causes bones to become weak and easy to break. It is a concern for all older women, but especially for women with HIV. Bone loss occurs faster in women (and men) living with HIV than in people who do not have HIV. Some HIV medicines may also increase the <u>risk of</u> <u>osteoporosis</u>.

If you have questions about symptoms of the menopause or about osteoporosis, talk to your health care team.

# Heart Disease and HIV

HIV-related heart disease is a leading cause of death among people living with HIV even when they are on consistent, effective HIV treatment.

The risk of heart attack is especially a concern for women. Women living with HIV are three times more likely to have a heart attack than women without HIV.

<u>Research is underway</u> to learn how factors unique to women with HIV affect heart disease risk and what to do about it.

# **Pregnancy and HIV**

Women with HIV can have healthy pregnancies. But some may need to switch HIV medications. Talk with your provider if you are thinking of planning a pregnancy, including about how to prevent transmission if your partner is HIV-negative.

In addition, women with HIV can pass the virus to their baby during pregnancy, childbirth, or breastfeeding. The good news is that there are <u>ways to lower the risk of passing HIV</u> to your unborn baby to 1% or less.

# **Birth Control and HIV**

Women with HIV can safely use any form of birth control to prevent pregnancy. But some HIV medicines can interact with hormonal <u>birth control</u>, including the shot, pills, or implants. This can raise the risk for pregnancy. Talk to your health care provider about which form of birth control is right for you.

Also, using condoms the <u>right way</u> every time you have sex can help reduce your risk of getting STDs such as gonorrhea and syphilis.



Content Source: <u>HIV.gov</u> Date last updated: May 23, 2019

# **Chapter VII. Living Well with HIV**

# A. Taking Care of Yourself 1. Aging with HIV

**Growing Older with HIV** 



At the start of the epidemic more than 30 years ago, people who were diagnosed with HIV or AIDS could expect to live only 1-2 years after that diagnosis. This meant that the issues of aging were not a major focus for people with HIV disease.

But today, thanks to improvements in the effectiveness of treatment with HIV medicine (called antiretroviral therapy or ART), people with HIV who are diagnosed early in their infection, and who get and stay on ART, can keep the virus suppressed and live long and healthy lives. For this reason, nearly half of people living with diagnosed HIV in the United States are aged 50 and older. Many of them have been living with HIV for years; others are recently infected or diagnosed. According to the Centers for Disease Control and Prevention (CDC), people aged 50 and older accounted for 17% of the 39,782 new HIV diagnoses in 2016 in the United States.

# Complications Associated with Aging

So the good news is that people with HIV are living longer, healthier lives if they are on treatment and achieve and maintain a suppressed viral load. However, with this longer life expectancy, individuals living with long-term HIV infection exhibit many clinical characteristics commonly observed in aging: multiple chronic diseases or conditions, the use of multiple medications, changes in physical and cognitive abilities, and increased vulnerability to stressors.

# Complications Associated with Long-term HIV Infection

While effective HIV treatments have decreased the likelihood of AIDS-defining illnesses among people aging with HIV, HIV-associated non-AIDS conditions are more common in individuals with long-standing HIV infection. These conditions include cardiovascular disease, lung disease, certain cancers, HIV-Associated Neurocognitive Disorders (HAND), and liver disease (including hepatitis B and hepatitis C), among others.

In addition, HIV appears to increase the risk for several age-associated diseases, as well as to cause chronic inflammation throughout the body. Chronic inflammation is associated with a number of health conditions, including cardiovascular disease, lymphoma, and type 2 diabetes. Researchers are working to better understand what causes chronic inflammation, even when people are being treated with ART for their HIV disease.

HIV and its treatment can also have profound effects on the brain. Although AIDSrelated dementia, once relatively common among people with HIV, is now rare, researchers estimate that more than 50 percent of people with HIV have HAND, which may include deficits in attention, language, motor skills, memory, and other aspects of cognitive function that may significantly affect a person's quality of life. People who have HAND may also experience depression or psychological distress. Researchers are studying how HIV and its treatment affect the brain, including the effects on older people living with HIV.

For more information, see the National Institute on Aging's Aging with HIV: Responding to an Emerging Challenge.

# Late HIV Diagnosis

Older Americans are more likely than younger Americans to be diagnosed with HIV infection late in the course of their disease, meaning they get a late start to treatment

and possibly more damage to their immune system. This can lead to poorer prognoses and shorter survival after an HIV diagnosis. Late diagnoses can occur because health care providers may not always test older people for HIV infection, and older people may mistake HIV symptoms for those of normal aging and don't consider HIV as a cause.

According to CDC, in 2016, 35% of people aged 50 and older already had late-stage infection (AIDS) when they received an HIV diagnosis (i.e., they received a diagnosis late in the course of their disease). But that percentage has declined since 2011, when 42% already had late stage infection.

# The Importance of Support Services

Living with HIV presents certain challenges, no matter what your age. But older people with HIV may face different issues than their younger counterparts, including greater social isolation and loneliness. Stigma is also a particular concern among older people with HIV. Stigma negatively affects people's quality of life, self-image, and behaviors, and may prevent them disclosing their HIV status or seeking HIV care.

Therefore, it is important for older people with HIV to get linked to HIV care and have access to mental health and other support services to help them stay healthy and remain engaged in HIV care. You can find support services through your health care provider, your local community center, or an HIV service organization. Or use the HIV Services Locator to find services near you.

**Content Source:** HIV.gov **Date last updated:** September 13, 2019

# 2. Employment and Health

# Working with HIV

With proper care and treatment, many people living with HIV lead normal, healthy lives, including having a job. Most people living with HIV can continue working at their current jobs or look for a new job in their chosen field. Your overall well-being and financial health can be more stable when you are gainfully employed.

# Getting a New Job or Returning to Work

Working will affect a lot of your life: your medical status, your finances, your social life, the way you spend your time, and perhaps even your housing or transportation needs. Before taking action on getting a new job or returning to work, you may want to get information and perspectives from:

- Your HIV case manager or counselor, if you have one
- Benefits counselors at an HIV service organization or other community organization
- The Social Security Administrations Work Incentives Planning and Assistance Program (WIPA)
- Other people living with HIV who are working, or have returned to work
- Providers of any of your housing, medical, or financial benefits
- Public and non-profit employment and training service providers

Here are some questions to discuss with them:

- What are my goals for employment?
- What kind of work do I want to do?
- What are the resources that can help me set and achieve a new career goal?
- Are there state or local laws that further strengthen anti-discrimination protections in the American Disabilities Act (ADA)?
- How do I access training or education that will help me achieve my goals?
- How can I plan to take care of my health if I go to work?
- How will my going to work impact the benefits I am receiving?

#### **Requesting Reasonable Accommodations**

Qualified individuals with disabilities, including people living with HIV, have the right to request reasonable accommodations in the workplace. A reasonable accommodation is any modification or adjustment to a job or work environment that enables a qualified person with a disability to apply for or perform a job. An accommodation may be tangible (for example, a certain type of chair) or non-tangible (for example, a modified work schedule for someone with a medical condition requiring regular appointments with a health care provider). You are qualified if you are able to perform the essential functions of the job, with or without reasonable accommodation.

Your supervisor may not be trained in reasonable accommodations or know how to negotiate them. For that reason, often its best to go directly to the person responsible

for human resources at your employer, even if that person works in a different location. In a small business, that person may well be the owner.

When you request an accommodation, state clearly what you need (for example, time off for a clinic visit every third Tuesday of the month, a certain type of chair, or a change in your work hours) and be ready to supply a doctors note supporting your request. The initial note need not contain your diagnosis, but it should verify that you are under that doctors care and that he/she believes you need the accommodation to maintain your health or to be able to fulfill essential functions of your job.

Many people living with HIV do not want to give a lot of details about their health. If you prefer not to provide a lot of information, you may want to limit the medical information you initially give to your employer. However, if your need for accommodation is not obvious, your employer may require that you provide medical documentation to establish that you have a disability as defined by the ADA, to show that the employee needs the requested accommodation, and to help determine effective accommodation options. This can, but often does not, include disclosing your specific medical condition.

Be aware that not all people with HIV or AIDS will need accommodations to perform their jobs and many others may only need a few or simple accommodations. The U.S. Department of Labors (DOL) Job Accommodation Network (JAN) provides free, expert, and confidential technical assistance to both employees and employers on workplace accommodations and disability employment issues, which includes resources for employees living with HIV or AIDS. See AskJAN.org , or call 800-526-7234 (voice) or 877-781-9403 (TTY) for one-on-one guidance.

**Content Source:** HIV.gov, and Office of Disability Employment Policy U.S. Department of Labor

Date last updated: May 15, 2017

# **3. Exercise and Physical Activity**

Should People Living with HIV Exercise?

Yes! Being HIV-positive is no different from being HIV-negative when it comes to exercise. Regular physical activity and exercise are part of a healthy lifestyle for everyone, including people living with HIV.

# What Are the Benefits of Physical Activity?

Physical activity has many important benefits. It can

- 1. Boost your mood
- 2. Sharpen your focus
- 3. Reduce your stress
- 4. Improve your sleep

You know you need physical activity to stay healthy. But did you know it can help you feel better right away?





Boost your mood Sharpen your focus Reduce your stress Improve your sleep <u>Health.gov/Move Your Way</u>: What's Your Move

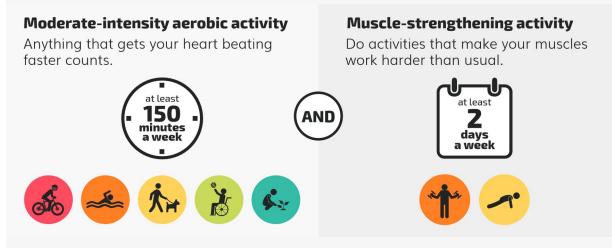
Physical activity can also help you reduce your risk of developing cardiovascular disease, high blood pressure, type 2 diabetes, and several types of cancer. These are all <u>health conditions</u> that can affect people living with HIV.

# How Much Activity Should You Do?

According to the evidence-based <u>Physical Activity Guidelines</u> (2018), adults need at least 150 to 300 minutes per week of **moderate-intensity aerobic activity**, like biking, brisk walking, or fast dancing. Adults also need **muscle-strengthening activity**, like lifting weights or doing push-ups, at least 2 days per week.



# How much activity do I need?



Tight on time this week? Start with just 5 minutes. It all adds up!

Health.gov/Move Your Way: What's Your Move

If you're living with HIV or have another chronic health condition, talk to your health care provider or a physical activity specialist to make sure these guidelines are right for you.

The most important thing is to move more and sit less!

#### What Types of Activity Are Right for People Living with HIV?

People living with HIV can do the same types of physical activity and exercise as individuals who do not have HIV.

Physical activity is any body movement that works your muscles and requires more energy than resting. Brisk walking, running, biking, dancing, jumping rope, and swimming are a few examples of physical activity.

Exercise is a type of physical activity that's planned and structured with the goal of improving your health or fitness. Taking an aerobics class and playing on a sports team are examples of exercise.

Both are part of living healthy.

Take time to find a fitness routine that you enjoy. You may consider taking part in a group activity that allows you to engage with others. Make it fun, and commit to being physically active regularly.

**Content Source:** <u>HIV.gov</u> **Date last updated:** January 02, 2019

# 4. Food Safety and Nutrition

# Why Is a Good Diet Important for People with HIV?

Good nutrition is important to all people—whether or not they are living with HIV. But some conditions related to treating HIV or AIDS (including wasting, diarrhea, and lipid abnormalities) mean that proper nutrition is really important to people with HIV. Eating well is key to maintaining strength, energy, and a healthy immune system. In addition, because HIV can lead to immune suppression, food safety and proper hygiene are concerns when it comes to preventing infections.

For more information, see the Department of Veterans Affairs' HIV/AIDS: Diet and Nutrition

A healthy diet is essential to maintaining good health across your lifespan. The U.S. Food and Drug Administration (FDA) defines a healthy diet as one that: provides enough of each essential nutrient; contains a variety of foods from all of the basic food groups; provides adequate energy to maintain a healthy weight; and does not contain excess fat, sugar, salt, or alcohol. There are six essential nutrients:

- *Protein* builds muscles and a strong immune system.
- *Carbohydrates* (including starches and sugars) give you energy.
- *Fat* gives you extra energy.
- Vitamins regulate body processes.
- *Minerals* regulate body processes and also make up body tissues.
- *Water* gives cells shape and acts as a medium in which body processes can occur.

For more information about healthy eating, see FDA's Smart Nutrition 101: FAQs.

Before you make major changes in your diet, however, contact your primary care provider, or a registered dietician who specializes in HIV care, to get a better assessment of your nutritional needs.

# What Do You Need to Know About Food Safety?

Because HIV affects your immune system, you may be at greater risk for food-borne illness. So in addition to eating well, you need to eat safely. By following a few basic safety rules when you prepare and eat your meals, you can protect yourself from food-related illness:

- Avoid eating raw eggs, meats, or seafood (including sushi and oysters/shellfish).
- Wash fruits and vegetables thoroughly.
- Use a separate cutting board for raw meats.
- Wash hands, utensils, and cutting boards with soap and water after each use.
- Water safety is extremely important, as water can carry a variety of parasites, bacteria, and viruses. To protect yourself against these infections, here are some helpful hints:
  - Do not drink water from lakes, ponds, rivers, or streams.
  - You may choose to use a store-bought water filter at home for your drinking water.
  - You can significantly reduce your risk of water-borne illness by using only boiled water for drinking and cooking.
  - When traveling abroad in areas where sanitation is poor or water safety is questionable, drink only bottled water and avoid ice or unpasteurized juices and drinks.

Content Source: HIV.gov Date last updated: May 15, 2017

# 5. Housing and Health

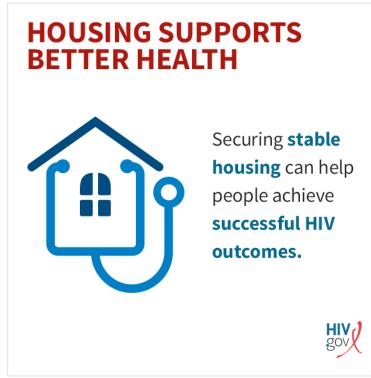
## Why Do People with HIV Need Stable Housing?

Stable housing is closely linked to successful HIV outcomes. With safe, decent, and affordable housing, people with HIV are better able to access medical care and supportive services, get on HIV treatment, take their HIV medication consistently, and see their health care provider regularly. In short: the more stable your living situation, the better you do in care.

Individuals with HIV who are homeless or lack stable housing, on the other hand, are more likely to delay HIV care and less likely to access care consistently or to adhere to their HIV treatment.

Throughout many communities, people with HIV risk losing their housing due to such factors as stigma and discrimination, increased medical costs and limited incomes or reduced ability to keep working due to HIV-related illnesses.

# What Federal Housing Assistance Programs Are Available for People with HIV?



To help take care of the housing needs of low-income people living with HIV and their families, the U.S. Department of Housing and Urban Development's (HUD) Office of HIV/AIDS Housing manages the Housing Opportunities for Persons With AIDS (HOPWA) program. The HOPWA program is the only Federal program dedicated to addressing the housing needs of people living with HIV. Under the HOPWA Program, HUD makes grants to local communities, States, and nonprofit organizations for projects that benefit low-income people living with HIV and their families. (View grantee <u>eligibility</u> requirements.)

Many local HOPWA programs and projects provide short-term and long-term rental assistance, operate community residences, or provide other supportive housing facilities that have been created to address the needs of people with HIV.

**Find a HOPWA Grantee or Local Program:** Search HIV.gov's <u>HIV Services Locator</u> to search for housing assistance near you.

## Are People with HIV Eligible for Other HUD Programs?

In addition to the HOPWA program, people living with HIV are eligible for any HUD program for which they might otherwise qualify (such as by being low-income or homeless). Programs include public housing, the Section 8 Housing Choice Voucher Program, housing opportunities supported by Community Development Block Grants, the HOME Investment Partnerships Program, and the Continuum of Care Homeless Assistance Program.

**Find Housing Assistance:** If you are homeless, at risk of becoming homeless, or know someone who is, help is available. Use <u>HUD's Resource Locator</u> to find housing assistance programs near you.

**Access Other Housing Information:** Find <u>resources for homeless persons</u>, including, <u>youth</u>, <u>veterans</u>, and the <u>chronically homeless</u>, as well as <u>rental</u>, <u>homebuyer</u>, and <u>homeowner assistance</u>.

This page was developed in collaboration with HUD's Office of HIV/AIDS Housing.

**Content Source:** <u>HIV.gov</u> **Date last updated:** August 21, 2019

# 6. Traveling Outside the U.S.

## **Can I Travel Abroad with HIV?**

With proper treatment, people with HIV can lead healthy and active lives, including traveling for business and pleasure. However, traveling to other countries, particularly developing countries, may require some advance preparation and special precautions.

#### **Before You Travel**

**See your health care provider** or <u>travel medicine specialist</u> to discuss the medical risks you might face and what you should do to prepare for safe and healthy travel. Ideally, this conversation should take place at least 4-6 weeks before your scheduled departure.

Talk to your provider about the <u>places you plan to visit</u>. He or she may:

- **Recommend certain travel vaccines**. Most <u>travel vaccines</u> are made from killed bacteria or viruses and can be given safely to people with HIV and others with weakened immune systems. However, they may be less effective than in people with strong immune systems, and may not provide full protection. Your doctor may recommend blood tests to confirm that a vaccine was effective, or recommend additional precautions to keep you safe. Some vaccines are made from live viruses and many people with weakened immune systems should not take them. However, depending on the circumstances, the benefits of protection may outweigh the risks. Talk to your health care provider about what is recommended for you.
- Recommend you pack a supply of medicine like antibiotics to treat travelers' diarrhea, which can affect people with weakened immune systems.
- **Provide you with the name(s) of health care providers or clinics** that treat people with HIV infection in the region you plan to visit.
- Advise you on how to minimize the risk of malaria and other insect-borne diseases such as <u>dengue</u> and <u>yellow fever</u>, depending on your destination. People who have weakened immune systems can get seriously ill from malaria, so it's important to closely follow your doctor's instructions for taking the preventative medicine, which may include taking it for several weeks before and after the trip. You should also take steps to <u>avoid bug bites</u>: wear insect repellent, wear long pants and sleeves, and sleep under a net if your rooms are exposed to the outdoors.

Also, educate yourself about your insurance policies:

- Review your medical insurance to see what coverage it provides when you are away from home. You may purchase supplemental traveler's insurance to cover the cost of emergency medical evacuation by air and the cost of incountry care, if these costs may are not covered by your regular insurance. View the U.S. State Department's information on <u>insurance for overseas travel</u>.
- **Take proof of insurance**, such as a photocopy or scan your policy and send the image to an e-mail address you can access both in the United States and abroad. Leave a copy at home and tell your friends or family where it is located.

## When You Travel Abroad

Food and water in developing countries may contain germs that could make you sick.

Do not:

- eat raw fruit or vegetables that you do not peel yourself;
- eat raw or undercooked seafood or meat;
- eat unpasteurized dairy products;
- eat anything from a street vendor;
- drink tap water (in developing countries some hotels may purify their own water but it is safer to avoid it), drinks made with tap water, or ice made from tap water.

Do eat and drink:

- hot foods;
- hot coffee or tea;
- bottled water and drinks (make sure the seals are original and have not been tampered with);
- water that you bring to a rolling boil for one full minute then cool in a covered and clean vessel;
- fruits that you peel;
- wine, beer and other alcoholic beverages are also safe.

Be aware:

- **Tuberculosis** is very common worldwide, and can be severe in people with HIV. Avoid hospitals and clinics where coughing TB patients are treated. See your doctor upon your return to discuss whether you should be tested for TB.
- **Animal wastes**, such as fecal droppings in soil or on sidewalks, can pose hazards to individuals with weakened immune systems. Physical barriers, such as shoes, can protect you from direct contact. Likewise, towels can protect you from direct contact when lying on a beach or in parks. If you are in physical contact with animals, wash your hands thoroughly afterwards with soap and water.
- Take all your medications on schedule, as usual.
- Stick to your special diet, if you are on one.
- **Take the same precautions** that you take at home to prevent transmitting HIV to others.

## Are There Restrictions on Traveling Abroad?

Some countries restrict visitors with HIV from entering their borders or staying for long periods of time. Others permit discrimination on the basis of sexual orientation or gender identification. According to the <u>State Department</u>, more than 70 countries consider consensual same-sex relations a crime, sometimes carrying severe punishment. Before you travel internationally, be aware of the laws, policies, and practices in the country or countries you plan to visit. This information is usually available from the <u>consular offices of each country</u> or in the State Department's <u>country information summaries</u>, along with information about entry and exit requirements.

## Traveling to the U.S. from Other Countries

As of January 2010, travelers with HIV or AIDS are allowed entrance into the U.S.

## What Travelers' Health Resources Are Available?

<u>CDC's Yellow Book</u>, a guide to health information for international travelers is an excellent resource for anyone traveling overseas. The section <u>on</u> <u>Immunocompromised Travelers</u> has extensive information for people with HIV.

CDC's <u>Travelers' Health</u> website contains find information on:

- travelers' health for people with weakened immune systems
- travel health notices for destinations
- recommended vaccinations and precautions for destinations

Additionally, the <u>Guidelines for the Prevention and Treatment of Opportunistic</u> <u>Infections in Adults and Adolescents with HIV</u> contain information about immunization against malaria and other infections that may be useful.

Content on this page was adapted from the Centers for Disease Control and Prevention.

Content Source: <u>HIV.gov</u> Date last updated: August 19, 2019

# **Chapter VII. Living Well with HIV**

**B.** Your Legal Rights

# 1. Civil Rights

## Laws Protect People Living with HIV and AIDS

If you are living with HIV or AIDS, you are protected against discrimination on the basis of your HIV under **Section 504** of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (**ADA**). Under these laws, discrimination means that you are not allowed to participate in a service that is offered to others, or you are denied a benefit, because of your HIV disease.

For more information, see the Department of Justice's <u>website</u>.

For more information in the health care context, see the Office of Civil Rights' <u>Civil</u> <u>Rights: HIV/AIDS</u>.

## **Federal Law**

Both Section 504 and the ADA prohibit discrimination against qualified persons, including those with HIV/AIDS.

The ADA prohibits discrimination by employers, places of public accommodation, and state and local government entities. Section 504 prohibits health and human service providers or organizations that get Federal funds or assistance from discriminating against you because you are living with HIV/AIDS. Examples of entities that may be covered by the ADA and/or Section 504 include **hospitals, clinics, social services agencies, drug treatment centers, nursing homes, doctors' offices, dentists' offices, daycares, public pools, and fitness gyms**. Again, under these laws, discrimination means that you are not allowed to participate in a service that is offered to others, or you are denied a benefit, because of your HIV disease. The ADA also protects your family and friends from discrimination because of YOUR HIV status, based on their association with you.

For more information, see OCR's <u>Your Rights Under Section 504 and the Americans</u> <u>With Disabilities Act</u>.

## Privacy

The Office for Civil Rights (OCR) also enforces the Privacy Rule under the Health Insurance Portability and Accountability Act of 1996 (**HIPAA**), which protects the privacy of your health information and gives you the right to review and make corrections to your medical records. For more information, see OCR's <u>Health</u> Information Privacy, Protecting the Civil Rights and Health Information Privacy Rights of People Living with HIV, or How to File a Complaint.

**Content Source:** <u>HIV.gov</u> **Date last updated:** November 10, 2017

# 2. Workplace Rights

## HIV, Employment Discrimination, and the Law

The Americans with Disabilities Act of 1990 (ADA) prohibits employment discrimination on the basis of disability. The ADA, which covers employers of 15 or more people, applies to employment decisions at all stages. Court decisions have found that an individual with even asymptomatic HIV is protected under this law.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) addresses some of the barriers to healthcare facing people with HIV, as well as other vulnerable populations. HIPAA gives people with group coverage new protections from discriminatory treatment, makes it easier for small groups (such as businesses with a small number of employees) to obtain and keep health insurance coverage, and gives those losing/leaving group coverage new options for obtaining individual coverage.

The Family Medical Leave Act of 1993 (FMLA) applies to private-sector employers with 50 or more employees within 75 miles of the work site. Eligible employees may take leave for serious medical conditions or to provide care for an immediate family member with a serious medical condition, including HIV/AIDS. Eligible employees are entitled to a total of **12 weeks** of job-protected, unpaid leave during any **12-month period**.

The Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA) allows employees to continue their health insurance coverage at their own expense for a period of time after their employment ends. For most employees ceasing work for health reasons, the period of time to which benefits may be extended ranges from **18 to 36 months**.

## Filing a Charge of Employment Discrimination

Any individual who believes that his or her employment rights have been violated may file a charge of discrimination with the Federal Equal Employment Opportunity

Commission (EEOC). In addition, an individual, an organization, or an agency may file a charge on behalf of another person in order to protect the aggrieved person's identity.

For more information, see EEOC's <u>The ADA: Your Employment Rights as an Individual</u> <u>With a Disability</u>.

Content Source: <u>HIV.gov</u> Date last updated: May 15, 2017

## 3. Limits on Confidentiality

## **HIV Disclosure Policies and Procedures**

If your HIV test is positive, the clinic or other testing site will report the results to your state health department. They do this so that public health officials can monitor what's happening with the HIV epidemic in your city and state. (It's important for them to know this, because Federal and state funding for HIV services is often targeted to areas where the epidemic is strongest.)

Your state health department will then remove all of your personal information (name, address, etc.) from your test results and send the information to the <u>U.S. Centers for</u> <u>Disease Control and Prevention (CDC)</u>. CDC is the Federal agency responsible for tracking national public health trends. CDC does not share this information with anyone else, including insurance companies. For more information, see CDC's <u>HIV</u> <u>Testing Basics: Privacy</u>.

Many states and some cities have partner-notification laws—meaning that, if you test positive for HIV, you (or your healthcare provider) may be legally obligated to tell your sex or needle-sharing partner(s). In some states, if you are HIV-positive and don't tell your partner(s), you can be charged with a crime. Some health departments require healthcare providers to report the name of your sex and needle-sharing partner(s) if they know that information–even if you refuse to report that information yourself.

Some states also have laws that require clinic staff to notify a "third party" if they know that person has a significant risk for exposure to HIV from a patient the staff

member knows is infected with HIV. This is called "duty to warn." The <u>Ryan White</u> <u>HIV/AIDS Program</u> requires that health departments receiving money from the Ryan White program show "good faith" efforts to notify the marriage partners of a patient with HIV.

#### **Disclosure Policies in Correctional Facilities**

Any individual who believes that his or her employment rights have been violated may file a charge of discrimination with the Federal Equal Employment Opportunity Commission (EEOC). In addition, an individual, an organization, or an agency may file a charge on behalf of another person in order to protect the aggrieved person's identity.

For more information, see EEOC's <u>The ADA: Your Employment Rights as an Individual</u> <u>With a Disability</u>.

Content Source: <u>HIV.gov</u> Date last updated: May 15, 2017

Chapter VIII is entirely derived and adapted from the Institutes of Health's National Library of Medicine, National Center for Biotechnology Information, SAMHSA/CSAT, Treatment Improvement Protocols. https://www.ncbi.nlm.nih.gov/books/NBK64930/

## **Chapter VIII. Counseling Clients With HIV**

## A. Staff Training, Attitudes, And Issues

Before conducting any screening, assessment, or treatment planning, counselors should reassess their personal attitudes and experiences in working with **HIV**-infected clients. This section discusses several ways in which counselors can accomplish this, including formal training within the program, examining personal attitudes (e.g., countertransference and homophobia), examining fears of infection, and avoiding burnout. It is important to reassess comfort levels with each client because each client will vary in demographic and cultural background. For instance, a service provider may feel comfortable working with a young Asian American male with a history of alcohol use, yet the same provider may not be at

all comfortable with a pregnant Hispanic woman who is an active injection drug user and wishes to have her baby.

## **B.** Training

Staff members must have the proper training to screen, assess, and counsel clients. Achieving staff competency is an ongoing process. The complexities related to people with **HIV**/AIDS is constantly changing and does not allow staff members to defer learning or training or even to maintain a "status quo" attitude about their competency.

Examples of methods to help staff grow in the areas of assessment, screening, and treatment planning include the following (see also the section "Cultural Competency Issues" later in this chapter):

- *Model skills and competencies*. Less experienced staff can observe supervisors or more tenured staff who demonstrate desired qualities.
- *Peer training and feedback.* Peer teams can provide feedback through direct observation of staff members' interactions with clients, as well as review of staff members' client charts.
- *Case presentations*. Weekly or monthly group case presentations conducted by a different staff member each time can be effective for building skills and monitoring quality. Case simulation, in which each staff member has an opportunity to ask the "client" a question, is a highly useful training tool. At the end of the presentation, everyone attending can provide feedback about the activity.

 Experiential skills-building exercises. Many activities can be used to sensitize staff to the client's experiences. Activities can include encouraging staff members to go to a confidential and anonymous HIV/AIDS test site, or anonymously sit in the waiting room of the local food stamp office, HIV/AIDS clinic, or county jail. Staff must use different avenues to maintain a keen sensitivity to and awareness of the client's issues.

- Assessment instruments. Use specific assessment tools, such as substance abuse and sexual history questionnaires.
- *Formal conferences, training, consultations with clinicians*. Often agency budgets are tight, and the first expense to be cut is staff development. This is a major problem for many programs. Programs must establish that improvement and excellence are serious goals and that attending treatment-

oriented conferences is a part of building staff competency and moving toward these goals.

## C. Attitudes

It is important that counselors be aware of any of their own attitudes that might interfere with helping a client. By learning to put aside personal judgments and focus on client needs, staff members can build trust and rapport with the client. When a counselor can deal with a client in a sensitive, empathic manner, there is a much greater chance that both will have a positive and successful encounter.

*Countertransference* is a set of thoughts, feelings, and beliefs experienced by a service provider that occurs in response to the client. Although sometimes these beliefs and feelings are conscious, generally they are not. It is thus unrealistic to expect counselors, usually untrained in addressing unconscious mental processing, to be aware of countertransference. Regular clinical supervision, which should be integrated into the staffing of the program, can help raise their awareness. If such resources exist, counselors may, with caution, address this issue.

In order to deal with countertransference issues, counselors must be willing to examine their skills and attitudes. Working with clients who have **HIV**/AIDS brings up issues for treatment staff that can be both physically and emotionally demanding. Counselors see a broad range of diverse clients from all walks of life. To work in these fields, providers must learn to be comfortable in discussing topics they may never have talked about openly--sex, drug use, death, grief, and so on. To effect positive change, counselors also must be willing to seek additional specialized training and support.

## D. Examining attitudes and skills

Countertransference can manifest itself in many different ways. The key to seeing countertransference issues is awareness and consciousness-raising. The commitment to "do no harm" to clients and their families, along with a desire to provide quality services, should be the driving forces for willingly examining these issues.

Following are some common countertransference issues for providers working with clients who are **HIV** positive (adapted from National Association of Social Workers, 1997):

- Fear of contagion
- Fear of the unknown

- Fear of death, dying, grief, and loss
- Stigmatization (e.g., of people with mental health problems, "addicts," people who are **HIV** positive, homosexuals)
- Powerlessness, helplessness, and loss of control
- Shame and guilt
- Homophobia
- Anger, rage, and hostility
- Frustration
- Overidentification
- Denial
- Differences in culture, race, class, and lifestyle
- Fantasies of professional omnipotence
- Burnout
- Measures of success and personal reward

## E. Issues

#### 1. Homophobia

To be aware of homophobic responses among treatment professionals and of their own countertransference issues, it is important that counselors understand how the client is handling his homosexuality.

In regard to the issue of homophobia, it is also critical to understand how stereotypes affect the treatment options offered. The professional should take an inventory of these stereotypes to assess her homophobia potential and should be aware of the roles countertransference can play. The short assessment tool provided in Figure 7-2 can be used to examine where providers and clients alike might rank on a continuum of homophobic reactions. This tool is also useful in group supervision sessions or discussions with both gay/lesbian and heterosexual colleagues.

#### Figure 7-2: Homophobia Questionnaire for Counselors and Clients

- Do you ever stop yourself from doing or saying certain things because someone might think you are gay or lesbian? What kinds of things?
- Do you ever intentionally do or say things so that people will think you're not gay/lesbian? What kinds of things?
- Do you think that lesbians or gays can influence others to become homosexual?
- Do you think someone could influence you to change your sexual orientation?
- If you are a parent, how would you (or do you) feel about having a lesbian daughter or a gay son?
- How do you think you would feel if you discovered that one of your parents, a parent figure, or a brother or sister were gay or lesbian?
- Are there any jobs, positions, or professions that you think gays and lesbians should be barred from holding or entering? Which ones and why?
- Would you go to a physician whom you knew or believed to be gay or lesbian if he or she were a different gender from you? If he or she were the same gender as you? If not, why not?
- If someone you cared about said to you, "I think I'm lesbian or gay," would you suggest that the person see a therapist?
- Have you ever been to a gay or lesbian social club, party, bar, or sporting event? If not, why not?
- Would you wear a button that says, "How dare you assume that I'm heterosexual?" If not, why not?
- Can you think of three positive aspects of a lesbian or gay lifestyle? Can you think of three negative aspects of a heterosexual lifestyle?
- Have you ever laughed at or told a "queer" joke?

It is important that counselors have a working knowledge of some of the terminology and definitions pertaining to homophobia. Following is a brief list of terms and definitions.

- Overt homophobia includes violence, verbal abuse, and name-calling.
- *Institutional homophobia* describes the way in which governments, businesses, schools, churches, and other institutions and organizations treat people differently and less favorably based on their sexual orientation.

- *Cultural homophobia* includes social standards and norms requiring heterosexuality.
- *Internalized homophobia* is acceptance and integration by lesbians and gays of the negative attitudes expressed by society toward them.
- *Heterosexism* is the system of advantages bestowed on heterosexuals. It is the institutional form of homophobia that assumes all people are or should be heterosexual and therefore excludes the needs, concerns, and life experiences of lesbians, gays, and bisexuals.
- *Coming out* may possibly be the most important part of gay and lesbian development. This is the process, often lifelong, in which a person acknowledges, accepts, and in many cases appreciates his or her own lesbian, gay, bisexual, or transgender identity. This often involves sharing this information with others. Family members of gay and lesbian individuals go through a similar process.
- *Oppression* is the systematic subjugation of a particular social group by another group with access to social and political power, by withholding access to that power.
- *Lesbian/gay baiting* involves actions or words that imply or state that the presence of a gay man or lesbian hurts or discredits a social system. The purpose is to hurt, demean, intimidate, or control, and to stop social change or acceptance of lesbians and gays within the social system.

These definitions can help the counselor become aware of the added layer of discrimination felt by gay men and lesbians in treatment for **HIV**/AIDS. Following is a list of some "Do's" to keep in mind when working with homosexual clients (adapted from Storms, 1994).

- Identify the lesbian/gay client's strengths and accept them as you find them.
- Listen empathically and refrain from making judgments about the client's lifestyle.
- Remain aware of the client's sexual orientation and the possible effects of this orientation on the client's experience and world-view.
- Explore the client's sexual practices with an eye toward internalized homophobia.
- Be aware of your own preference and mindful of possible homophobia or confusion in your own sexual identity.

- Be knowledgeable about compulsive sexual behavior and sexual practices in the lesbian/gay community.
- Ask your lesbian/gay clients what terms they prefer when discussing their sexual orientation and those of others.
- Encourage self-empowerment, consciousness-raising, and participation in the lesbian and gay community.
- Encourage your program to hire openly lesbian and gay counselors/therapists.
- Educate others about internalized homophobia and heterosexism. Be gayand lesbian-affirming rather than just gay- and lesbian-tolerant.
- Stay abreast of current information on resources and display this information in your office. Attend seminars and professional workshops about working with lesbian and gay clients.

## 2. Fear of infection

Fear of infection is one of the most challenging issues for counselors. It is essential that providers examine this issue without blaming or judging themselves and others. Professionals who work with **HIV**-positive individuals may have thought about becoming infected with **HIV** through their work. Some may fear that scientists are not aware of modes of infection or transmission that might put service providers and their families at greater risk of infection (<u>Montgomery and Lewis, 1995</u>). The key to dealing with this fear is to discuss it and vent the feelings with someone who is safe, trusted, and informed, *and* to practice universal precautions at all times.

Beyond this, it is essential for providers to have regular and frequent inservice training with updates on the latest research and data about transmission and treatment of **HIV**/AIDS.

# F. Special considerations for counselors who treat HIV-infected clients

The challenges and stresses related to working with people with **HIV**/AIDS are in some ways unique. The fact that providers often deal with multiple and serial losses and see clients suffering on a daily basis clearly affects the providers' psychological health. In recent years, therapists have begun to examine and assess these service providers for symptoms of posttraumatic stress disorder (PTSD).

Burnout often is referred to as "bereavement overload." One definition characterizes burnout as lowered energy, enthusiasm, and idealism for doing one's job, that is, as a loss of concern for the people served and for the work (<u>Hayter</u>, <u>1999</u>). Unlike fatigue, burnout does not resolve after a given amount of rest and recreation.

Burnout prevention and stress management techniques should be used both in the work setting and in counselors' personal lives. Working with **HIV**-infected clients requires agencies and individuals to be more creative and flexible in finding new and different ways to support and nurture counselors to prevent burnout. Agencies that have taken on this challenge with integrity and commitment have seen highly effective staff function at optimal levels for many years.

Suggestions for ways in which agencies can take care of counselors at work include

- Assigning clearly specific duties
- Having clear boundaries on professional obligations
- Enlisting volunteer help from community organizations
- Allowing for "time out" activities
- Varying tasks and responsibilities
- Building in "mental health days"
- Providing for continuing education
- Holding staff retreats (with enjoyable activities planned)
- Holding discussion, process, and support groups
- Convening regular staff/team supervision meetings

In addition, it is important that agencies allocate time to discuss the deaths and losses faced by staff. This may mean supporting special memorial events at which those who have been lost to **HIV**/AIDS disease can be remembered. Agencies also can support staff through contracts with employee assistance program therapists and by providing an onsite therapeutic support group for staff members to attend as they wish.

## G. Screening

## 1. Primary medical care

Primary medical care should consist of a comprehensive physical exam, treatment for **HIV**/AIDS, and treatment for opportunistic infections.

## 2. Mental health care

A diagnosis of mental illness may reflect the client's affective and mood responses to this medical judgment, may be a consequence of self-medication, or may reflect neurological complications of **HIV**/AIDS, as well as an underlying mental health disorder. Mental health care should consist of both a neuropsychiatric workup and full mental health status examinations. Service providers should be alert to and notify clients and psychiatrists that complications may arise from the use of prescription medication for mental health problems and medications for **HIV**/AIDS and opportunistic infections.

## 3. Nutritional care

If the client is also a substance-abusing client, then living with **HIV**/AIDS is typically mal- or undernourished because of street lifestyles, the effects of **HIV** disease, and the physical effects of substance abuse. This combination typically results in diminished appetite, weight loss (especially of lean muscle mass), poor hygiene, immune suppression, protein deficiencies, vitamin and mineral exhaustion, and anemia. In addition, providers should be aware that apparent lack of nutrition is not associated with digestive disease or parasites.

Good nutrition is a fundamental part of overall medical care. It improves strength, energy, longevity, and quality of life; increases muscle mass and body weight; decreases likelihood of hospitalization and length of stay; and slows progression of **HIV** to AIDS.

Without adequate nutrition, **HIV**/AIDS clients can easily develop malnutrition. Various causes of malnutrition and weight loss include

- Inadequate intake of food
- Anorexia
- Malabsorption of food
- Altered metabolism
- Food and drug interactions
- Androgen deficiency

- No cooking facilities
- Limited income
- Reliance on community food programs

With the onset of malnutrition, the client loses weight and experiences several body composition changes. *Starvation* results in loss of body fat and muscle. *Wasting syndrome* produces a loss of a serious percentage of body weight, with accompanying diarrhea and fever, and has been considered a defining symptom of AIDS since 1987. The degree of loss of lean body mass may indicate the length of time that the client has left to live.

## 4. Lipodystrophy syndrome

Lipodystrophy syndrome occurs in early end-stage AIDS and produces altered body composition and various hormonal and physiological changes. The cause of the syndrome and its relationship with **HIV** and protease inhibitors are unknown. Because of the disfiguring nature of some symptoms, lipodystrophy can be particularly distressing for women. Symptoms include

- Redistribution of body fat
- Increase in waist size
- Thinning of the arms and legs
- Increased facial wrinkling
- Weakness and muscle wasting
- Gastrointestinal symptoms
- Increased triglycerides and cholesterol
- Decreased testosterone levels
- Hypertension
- Diabetes

To determine body composition changes, provider staff should recommend that clients be measured on a bioelectrical impedance analysis machine. This noninvasive machine sends a weak electrical current through electrodes placed on the client's hands and feet to measure fluid volume, blood cell mass, extracellular mass, and level of body fat. Repeated every 3 to 6 months, this procedure can provide an accurate gauge of the client's biophysiological status.

Providers can treat weight loss and malnutrition by prescribing a nutritious, balanced diet with plenty of fluids and a daily multivitamin, if needed. Protein and calorie supplements are recommended if the client is losing weight. The client should avoid toxic substances such as alcohol, tobacco, and recreational drugs and should practice a daily routine of moderate exercise. Pharmaceutical interventions that may be required include appetite stimulants, thalidomide, and growth hormones.

Treatment staff should also discuss integrative therapies with the client. These can include herbs, acupuncture, meditation, massage, yoga, chiropractic, homeopathic medicine, megadosing, tai chi, qigong, and various religious practices.

#### 5. Dental care

Persons living with **HIV**/AIDS may require extensive dental care, up to and including tooth extraction, possible jawline reconstruction, and possible dental plate replacement.

## 6. Ancillary services

The steady increase in the number of women living with **HIV**/AIDS is creating a great demand for ancillary services such as child care, housing, and transportation. Families needing housing may face long waiting lists for Section 8 housing or may receive Section 8 certificates only to find few landlords willing to accept Section 8 housing payments.

## H. Disclosure Issues

Disclosure issues are difficult for all **HIV**-infected clients. For example, disclosure of positive **HIV** status may lead to personal threats or harm to both client and family. A client's family may refuse to associate with him upon learning of his **HIV**/AIDS status. Particularly for clients whose culture reflects definition of self within a community or self in relation to a clan (as opposed to individual definition), separation from community can serve as a trigger for lapse or relapse into risky substance use and sex-related behaviors. Therefore, providers must use caution when notifying clients of test results and should comply with regulations to ensure that a client's confidentiality is preserved.

Also, for **HIV** clients who are also substance abusers, during group therapy clients may feel an obligation to reveal their **HIV** status to the rest of the group. Counselors should caution clients about the impact of such disclosure and consider discouraging them from making it. Clients who wish to disclose their **HIV** status generally do so in response to treatment themes of honesty and openness and are not completely aware of the consequences. Of course, in treatment settings where all patients are **HIV** positive, there is no need for this concern.

## I. HIV/AIDS-Specific Counseling Issues

There are many counseling issues specific to **HIV**/AIDS that providers should be familiar with when treating **HIV**-infected clients.

## 1. Cultural Competency Issues

Culture is the integrated pattern of human behavior that includes thoughts, speech, actions, and artifacts. Culture depends on the capacity of humans for learning and transmitting knowledge to succeeding generations. It takes into account the customs, beliefs, social norms, and material traits of a racial, religious, or social group. With this type of definition, it is easy to see that there is indeed a culture of addiction, a culture of poverty, a gay culture, and even a recovery culture.

Cross and colleagues present a comprehensive discussion of culturally competent systems of care. Five essential elements contribute to cultural competence (<u>Cross et al., 1989, pp. 19-21</u>), which can briefly be described as follows:

- 1. Valuing diversity. Counselors value diversity when they accept that the people they serve come from very different backgrounds and may make different choices based on culture. Although all people share common basic needs, there are vast differences in how people go about meeting those needs. Accepting the fact that each culture finds some behaviors, actions, or values more important or desirable than others helps workers interact more successfully with different people.
- 2. **Cultural self-assessment.** When counselors understand how systems of care are shaped by dominant cultures, it may be easier for them to assess how these systems interface with other cultures. Care providers can then choose actions that minimize cross-cultural barriers.
- 3. **Dynamics of difference.** When cultural systems interact, both representatives (e.g., care provider and client) may misjudge the other's actions based on history and learned expectations. Both will bring dynamics of difference--culturally prescribed patterns of communication, etiquette, and problem solving, as well as underlying feelings about serving or being served by someone who is different. Incorporating an understanding of these dynamics and their origins into the system enhances chances for productive cross-cultural interventions.

- 4. **Institutionalization of cultural knowledge.** Workers must have accurate cultural knowledge and information or access to such information. They also must have available to them community contacts and consultants to answer culturally related questions.
- 5. Adaptations to diversity. The previous four elements build a context for a cross-culturally competent system of care and service. Both workers' and systems' approaches can be adapted to create a better fit between needs of people and services available. For instance, members of certain ethnic groups repeatedly receive negative messages from the media about their culture. Programs can be developed that incorporate alternative culturally enhancing experiences, develop problem solving skills, and teach about the origins of stereotypes and prejudice. By creating and implementing such programs, workers can begin to institutionalize cultural interventions as a legitimate helping approach.

Finally, becoming culturally competent is a developmental process for individual counselors.

It is not something that happens because one reads a book, or attends a workshop, or happens to be a member of a minority group. It is a process born of a commitment to provide quality services to all and a willingness to risk. (Cross et al., 1989, p. 21)

## 2. Making culturally competent decisions

Treatment providers must examine two essential factors when working with culturally, racially, or ethnically different populations: the socioeconomic status of the client or group and the client's degree of acculturation. A distinction should be made when discussing a population as a whole and a particular segment of that population. For example, when treating an **HIV**-infected substance-abusing Hispanic woman, the counselor should focus on the woman as an individual and on the particular circumstances of this individual's life, rather than seeing her as an abstract representative of her culture or race. More often, poverty is the relevant issue to be discussed, rather than specific ethnic or racial factors (<u>Centers for Disease Control and Prevention [CDC], 1998j</u>).

The second factor, degree of acculturation, is important and should be part of the assessment process. How acculturated or assimilated are the family and client? What generation is this client? Assessing for this, and knowing that several generations with different values and levels of acculturation may all live in one household, can test the communication skills and counseling skills of the best

service providers. When discussing acculturation/ assimilation and values, counselors should keep in mind that, in general, the more years a family has lived in the United States, the less traditional their values tend to be. Thus a fourth-generation Chinese-American client may not speak Chinese or hold traditional Chinese values. Knowing the values and beliefs of a client is crucial if treatment is to be effective.

Providers must also help develop culturally competent systems of care. A part of this is making services accessible to and often used by the target risk populations. Culturally competent systems also recognize the importance of culture, cross-cultural relationships, cultural differences, and the ability to meet culturally unique needs (Cross et al., 1989).

Aside from assessing cultural competence using the five elements discussed previously, it also is helpful to examine some ways in which providers can minimize cultural clashes and blocks that may exist when working with clients. The guidelines given in Figure 7-3 are adapted from a project conducted by the University of Hawaii AIDS Education Project.

#### Figure 7-3: Guidelines To Minimize Cultural Clashes

- 1. Plan to spend more time with clients holding values different from yours. The relationship is more complex, and it may take longer to establish trust.
- 2. Anticipate that past frustrations with insensitive or inappropriate providers may have made the client angry, suspicious, and resentful.
- 3. Acknowledge past frustrations.
- 4. Acknowledge the difference between your own experience and that of the client's.
- 5. Individualize (the clear message of all treatment planning)-a client is more than an "addict," an Asian, or a person with HIV/AIDS. Get to know the whole person.
- 6. Encourage disagreement and negotiation to ensure a workable plan.
- 7. Anticipate multiple needs: medical, legal, social, and psychological.
- 8. Be prepared to advocate for the client who may not have the resources, knowledge, or experience to negotiate the HIV/AIDS and substance abuse services systems.
- 9. Assist the client in getting other resources.
- 10. Involve friends and family. This can help ensure that the client receives other needed services.
- 11. Pay attention to communication: nonverbal, expressive style, and word usage and meaning.

- 12. Make use of providers from other cultures.
- 13. Learn the strengths of a culture. In Hispanic culture, for example, the value of "respeto," demonstrating appropriate social respect, can be used to support an intervention plan.
- 14. Expect differences in beliefs about
  - Help-seeking behaviors
  - Caretaking/caregiving
  - Cause of disease/illness
  - Sexuality/homosexuality
  - Death and dying
  - Making eye contact and touching

Source: University of Hawaii AIDS Education Project.

One concern in providing culturally competent care is how to discuss values and differences around sex and sexuality. In many cultures, people avoid discussing sex because they find such discussions disrespectful. This is one reason why so many cultures avoid discussing homosexuality. A counselor should consider using a less direct approach when initiating discussion about issues related to sex and sexual orientation. Many providers believe that some of the public health problems faced in communities of color and the gay community are related to their inability to speak often and directly enough about safer sex practices, risky behaviors, and homosexuality. Even in the recovery culture and in many treatment settings, sex and sexuality are blatantly avoided. Service providers must acknowledge that they, too, in addition to their clients, are often uncomfortable talking about sexuality, sexual identity, and sexual orientation.

Providers also should be aware of the messages often given to communities of color and particularly women. The message, "stop having sex," often advocated by providers has been mixed with historical issues and fears of racial/ethnic genocide, thus making it difficult for most groups to give any credence to those expounding this method of reducing **HIV**/AIDS. The value of sex and procreation in many cultures makes it difficult for someone from outside the client's culture, especially someone of a different gender, to tell people to not have sex or to have sex only with a condom.

Finally, it is important that the counselor recognize that much of what is asked of clients and their families is personal and private. Questions related to sex, dying, and substance abuse are not usual topics of conversation, and when asking these questions, the counselor crosses many boundaries. It often is considered

disrespectful (and offensive to certain cultural values) to ask questions about these specific areas. One wise way to broach these subjects with clients, especially clients who are significantly older than the provider or from a more traditional culture, is to simply apologize

The most practical advice is for providers to (1) maintain an open mind, (2) use cultural consultants for training and support, and (3) when in doubt, defer to the concepts of health and stability over pathology and dysfunction.

<u>Figure 7-4</u> presents the LEARN model developed by Berlin and Fowkes, an excellent cross-cultural communication tool that can be useful in all client encounters, especially with clients who are culturally different from the provider and who have **HIV**/AIDS and substance abuse disorders.

#### Figure 7-4: The LEARN Model

L-Listen with empathy and understanding. Ask the client, "What do you feel may be causing the problem? How does this affect you?"

**E**-Elicit cultural information, explain your perception of the problem, have a strategy, and convey it to the client.

A-Acknowledge and discuss differences and similarities. Find areas of agreement and point out areas of potential conflicts so they can be discussed, understood, and resolved.

**R**-Recommend action, treatment, and intervention. Incorporate cultural knowledge to enhance acceptability of the plan.

N-Negotiate agreements and differences. Develop a partnership with the client and the family.

Source: Berlin and Fowkes, 1983.

#### J. Special Populations

#### 1. Gay, lesbian, bisexual, and transgender populations

Providers wishing to serve the needs of particular ethnic or cultural groups have learned that communities must be understood, respected, and consulted in order to make effective interventions; this also holds true when working with gay men, lesbians, and bisexual men and women. This population is defined not by traditionally understood cultural and ethnic minority criteria, but by having a sexual orientation that differs from that of the majority. Transgender people also form a unique population, often linked to gay men, lesbians, and bisexuals, although they differ from the majority by gender identification rather than sexual orientation. A sudden increase in the use of methamphetamine, known as "speed," "crystal," "ice," or "crank," by gay and bisexual men has become a matter of grave concern. A primary route of administration for this drug is injection. Combined with its disinhibiting and sexually stimulating effects, gay male injectors of methamphetamine are at extremely high risk for **HIV** exposure: The drug causes the abuser to suspend all judgment and leaves him often impotent but extremely sexually aroused and often an anal-receptive partner in sex (<u>Gorman</u>, <u>1996; Gorman et al.</u>, <u>1995</u>).

Men who have sex with men (or MSMs--the CDC category used to report its data) may self-identify as gay (men with homosexual sexual orientations), bisexual (men who feel sexually drawn to both men and women), or heterosexual (men having sex with men as a purely physical act and not a reflection of innate sexual orientation). No matter what their sexual orientation, unprotected sexual contact puts MSMs at risk for **HIV**. In most reviews of gay men and safer sex practices, most men who were knowledgeable about safer sex failed to practice it while under the influence of some substance (<u>Calzavara et al., 1993; Leigh, 1990; Leigh and Stall, 1993; Paul et al., 1994; Stall, 1987; Stall et al., 1986). Many men from minority backgrounds who have sex with other men do not self-identify as gay or bisexual, so interventions should be based not on sexual orientation, but on sexual behavior.</u>

Some women who have sex with women continue to have sex with men. A number of these women may be injection drug users and share syringes; consequently, they are prone to **HIV** infection. Although it is unlikely that female-to-female transmission of the virus will occur, lesbians have been urged to use safer sex precautions, such as using dental dams during oral sex (<u>White, 1997</u>).

Lesbians present some specific issues that must be highlighted. Compared with gay men, they are more likely to have lower incomes (as do women in general when compared with men); are more likely to be parents (about one-third of lesbians are biological parents); face prejudice as women as well as for being gay, including the stronger reaction against and willingness to ignore females with substance abuse disorders; are more likely to come out later in life (about 28 years of age versus 18 years of age in men); and are more likely to have bisexual feelings or experiences, so that they are still at sexual risk for **HIV** infection as well as possible IDU risk (Banks and Gartrell, 1996; Bell et al., 1981; Bradford and Ryan, 1987; Mosbacher, 1993).

Gay youth also present treatment challenges. Special sensitivity and understanding are needed to work with youth of any background, especially youth who are gay or lesbian or from an ethnic minority background. Young gay males in particular may

be subjected to harassment at home or school, and they are prone to alcohol use, dropping out of school, running away, and getting involved in sex for drugs or money (Ku et al., 1992; Rotheram-Borus et al., 1995; Savin-Williams, 1994). Many young gay male streetworkers abuse amphetamines, "tweaking" to have a sexual experience, and may exchange sex for drugs.

In general, gay men, lesbians, bisexuals, and transgender people are wary of the medical establishment and may resist seeking health care, distrust the advice given, or question the treatment plan suggested if the provider displays evidence of homophobia or heterosexism.

## Transgender individuals

The following definitions have been provided to clarify the confusion some providers may feel when working with transgender clients (CSAT, in press [b]).

Transgender people are a diverse group of individuals who cross or transcend culturally defined categories of gender. They can include the following:

- Male-to-female (MTF) and female-to-male (FTM) *transsexuals*--those who desire or have had hormone therapy or sex reassignment surgery
- *Cross-dressers* or *transvestites*--those who desire to wear clothing associated with another sex
- *Transgenderists*--those who live in the gender role associated with another sex without desiring sex reassignment surgery
- *Bigender persons*--those who identify as both man and woman
- *Drag queens* and *kings*--usually gay men and lesbian women who "do drag" and dress up in, respectively, women's and men's clothing
- *Female* and *male impersonators*--males who impersonate women and females who impersonate men, usually for entertainment

Gender identification is different from sexual orientation. *Gender identity* refers to a person's basic conviction of being male, female, or transgender. *Sexual orientation* refers to sexual attraction to others (men, women, or transgender persons). For example, many cross-dressers are heterosexual men who have active sexual relationships with women. Many homosexual men, although historically considered effeminate, identify strongly as men and appear very masculine.

Substance use plays a significant role in the high **HIV** prevalence in MTF transgender individuals (Longshore et al., 1993, 1998). One study that investigated

519 transgender individuals in San Francisco found high rates of substance abuse among both MTF and FTM individuals (<u>Clements et al., 1998</u>). The study reported that 55 percent of the MTF sample indicated they had been in substance abuse treatment at some time during their lifetime. The study also found that **HIV** prevalence was significantly higher among MTF individuals (35 percent) than FTM individuals (2 percent), and among the MTF individuals, **HIV** prevalence for African Americans was 61 percent. Although the **HIV** prevalence rate was low in the FTM individuals, they commonly reported engaging in many of the same **HIV** risk behaviors as the MTF individuals (<u>Clements et al., 1998</u>).

Figure 7-5: Guidelines for Working With Transgender Clients.

## <u>DO:</u>

- Use the pronouns based on their *self-identity* when speaking to or about transgender individuals.
- Obtain clinical supervision if you have reservations about working with transgender individuals.
- Allow transgender clients to continue the use of hormones when prescribed; advocate for the transgender client who is using "street" or illegally prescribed hormones to receive immediate medical care and legally prescribed hormones.
- Ensure that all clinic staff receive training on transgender issues.
- Ascertain a transgender client's sexual orientation before treating him or her.
- Allow transgender clients to use appropriate bathrooms and showers based on their *gender self-identity and gender role*.
- Require all clients and staff to create and maintain a hospitable environment for all transgender clients. Post a nondiscrimination policy, including sexual orientation and gender identity, in the waiting room.

## DON'T:

- Call someone who identifies as female "he" or "him," or someone who identifies as male "she" or "her."
- Make transphobic comments to other staff or clients.
- Leave it to the transgender client to educate clinic staff.
- Assume all transgender individuals are gay.

• Force transgender clients identifying as male to use female facilities; likewise, don't force those identifying as female to use male facilities.

#### 2. Women

The disease of **HIV**/AIDS presents differently in women than in men and progress at different rates for a variety of reasons, including the fact that women usually present later in the **HIV**/AIDS disease process than men.

Gender-specific services for women should include the following:

- Medical treatment that is accessible, available, and incorporates
  - General health (including reproductive health) and wellness across the life span
  - Mental health counseling (particularly for PTSD)
  - Parenting skills and support
  - Family-focused support
  - Relationship issues
  - Trauma/abuse support
  - Educational/vocational services
  - Legal services
  - Sexuality and sexual orientation issues
  - Eating disorder support
  - Women-only support groups
- Empowerment--that is, holistic programming that emphasizes the development of a partnership with a female service provider, one in which there are mutual respect and many opportunities for positive role modeling
- Transportation services
- Child care, both onsite and supervised
- Woman-sensitive women working with women

• Long-term case management services that extend to the client and her family

A woman's identity as caregiver/caretaker must be recognized as an extremely powerful factor in how she accesses care and treatment and how successful she is in her health maintenance. This is also a factor in a woman's sense of guilt and shame from becoming **HIV** infected--a societal stigma that only "bad girls" get **HIV** or are addicts or alcoholics, and the stigma of being an unfit mother if she has lost custody of her children.

Providers must be open and prepared to discuss safer sex from a risk-reduction perspective. They must be well informed about and comfortable in discussing sexuality. Risk reduction is an ongoing type of intervention that goes beyond assertiveness training and teaching women how to put condoms on men. It recognizes the need to "start where the client is" and use appropriate interventions, which may help a woman reduce her risk of getting re-infected or of infecting a partner. This includes instructing female injection drug users about how to use bleach to "clean their works," how to use a female condom, or how to use a vaginal spermicide foam (not the safest risk-reduction method, however) to lower their risk of **HIV** infection when having intercourse. It also involves instruction for male partners on how to use a condom correctly.

## **Rep**roductive decision making

Reproductive decision making is an important area for providers to examine with both female and male clients. Providers must be prepared to discuss pregnancy and family planning with respect and without judgment. This is a difficult task for providers and clients; counselors may have many judgments about "right" and "wrong" and many opportunities for countertransference. One way providers can interact with clients is to help them openly and honestly consider various factors when making reproductive decisions. Figure 7-6 is adapted from an article written by Rebecca Dennison, director of a women's health advocacy organization based in San Francisco, who is **HIV** positive and considered these issues with her husband in her own reproductive decision making.

#### Figure 7-6: Reproductive Decision making Questions

• Statistics and information are constantly changing. The latest research from NIH still supports the Pediatric AIDS Clinical Trials Group Protocol 076 study, which indicated that about 8 percent of women treated with AZT during pregnancy and delivery transmitted HIV to their infants. It is unclear to date what the long-term health ramifications are for children who received AZT in utero and at birth. Are you willing to run the risk of having a child who is infected or has been affected by medications used to counter HIV infection?

- Are you able and willing to love and care for a baby, whether or not it is infected?
- How will pregnancy affect your health? In women with high T-cell counts, pregnancy has not been shown to make HIV/AIDS progress, but less is known about women who have AIDS or symptomatic HIV disease.
- Do you have the support of a partner, family members, or friends who can help care for a child?
- Who will care for your child if you become sick or die? Will there be people who will teach your child about his culture, help your child remember you, and raise your child according to your values?
- In what ways (good or bad) will having a baby change your life?
- What are the reasons that you want (or do not want) to have a child?
- Do you have children now? How are things with them?
- Do you feel pressured by others (partners, family, friends, your religion, cultural values) to have (or not have) a child?
- Do you have a family physician or obstetrician who knows about HIV/AIDS and who can give you the health care that you need?
- Do you have enough information to make an informed decision? If not, find someone who can give you information and who will not insist on telling you what to do.
- Are you willing and able to go without substances for at least 9 months? Do you know how their use will affect your unborn child?

#### Source: Dennison, 1998, p. 7.

The questions listed in Figure 7-6 are extremely helpful, but it is also important to remember that many clients have never made reproductive decisions. One way to provide support in this area, and help build coping skills, is to encourage women to talk with other women--to become part of a support group that is based on empowerment and women helping women. Counselors should see reproductive decision making as a very high priority and move toward this goal in small, incremental steps.

At present, no one knows exactly how to predict which mothers will transmit **HIV** to their infants. Although there is some speculation that a mother's viral load, measured through viral load assays, may indicate whether her infant becomes **HIV** infected. Much is still unknown, and controversies abound, but providers must understand and respect the importance of self-determination and the right of women to make their own decisions. Ultimately, it is the woman's choice. Today, **HIV**-positive women are looking at the prospect of pregnancy differently than they did in 1989. **HIV**-positive women who think about becoming pregnant have access to information about viral load testing and the possibility of artificial insemination. Also, **HIV**-positive women can consider a natural rhythm method, identifying fertile days and limiting unprotected intercourse to those times to decrease their partner's risk of **HIV** infection. There is no question that even today, facing pregnancy while **HIV** positive, examining the options related to terminating or continuing a pregnancy, deciding about medications, examining the woman's health and the infant's health, and addressing the long-term implications are all complex issues.

It is essential that providers examine these issues with clients within the context of a biopsychosocial framework. Counselors and health care providers must work together, along with the female client, to stay aware of the latest research and information regarding **HIV**/AIDS treatment. It is also important to remember that data and information on **HIV**/AIDS are constantly changing and that the "facts" provided to clients today may be very different tomorrow.

## 3. Parents who are HIV positive

More and more resources have been developed for single- and two-parent households in which one or both parents are **HIV** positive and/or the children are **HIV** positive. There must be a continued awareness of the needs of these families.

These families experience the need for a variety of services, both child-centered and adult-centered. Concerns about guardianship for children after the parent is unable or unavailable to care for them must be a major focus for the parent and the service provider.

If a child also is **HIV** positive, there will be special needs that the parent may not be able to address while facing her own issues. The already demanding dynamics of childhood, school, and growing up become more challenging for an **HIV**infected child and parent. Even if the child is not **HIV** positive, the demands of parenting can prove rigorous for single parents with **HIV**/AIDS. Although the parent experiences the relief of knowing the child is all right, the poignant realization that he may not live to see that child grow up can still be painful.

The **HIV**-infected single parent with a substance abuse disorder is at risk of losing custody of her minor children if convicted of drug possession or substance abuse. If family members disapprove of the single parent's lifestyle, they may seek custody of the active substance abuser's minor children. The counselor may

facilitate a plan encouraging the single parent toward goals that support the parenting relationship. This enables the recovery process to take place while the parent and child are working out their own version of permanency planning.

There are support groups and programs for children whose parents are affected by **HIV**. Although not available in all communities, these groups offer children a chance to talk about their fears regarding their parents' health, learn more about the disease, and socialize with others who are facing these problems. At the same time, the programs can provide the parent with some respite time.

If service providers work in a large urban area, chances are there will be an AIDS Service Organization (ASO) listed in the phone book. This agency is likely to have lists of support groups of all kinds.

#### 4. Hispanics

The Hispanic population in the United States is diverse, composed of a wide range of racial, indigenous, and ethnic groups. The following are important statistics related to the U.S. Hispanic population that affect how outreach, prevention, and treatment planning should be conducted:

- Hispanics have the highest labor force participation rate of all groups.
- Hispanic men have the highest fertility rate of all groups across all ages.
- Hispanic men have the lowest divorce rate of all groups.
- Hispanic men are on average younger than other men in the United States (with median age of 26.2 years).
- 90 percent of Hispanics are Catholic.
- 36 percent of Hispanic children live below the poverty level.
- There is a clear increase in substance abuse as Hispanics become more acculturated (i.e., in second and third generations, and so on).
- Hispanics are overrepresented among **HIV**/AIDS cases for men, women, and children.
- Hispanics as a group may include aliens who are undocumented or carry immigrant visas (green cards) and who avoid contact with the health care system because they fear possible deportation.

Within the context of acculturation and socioeconomic status, providers should be aware of specific cultural issues that can support interventions and improve a

provider's ability to engage Hispanic clients, such as the role of the family, the values of interdependence, respect, and "personalismo" (i.e., importance of personal contact). Understanding these concepts will help establish rapport and trust.

The Hispanic family is generally extended and has many members. A Hispanic client's support system may be composed of siblings, godparents, aunts, and uncles who are all very involved with the client. The family as a whole is of great importance, and often what is best for the family will override what is best for one of its members. Because the family is so important to most Hispanics, children are highly valued. This makes it easier to see how some Hispanic women who are **HIV** positive grieve deeply about the decision not to have children and may feel unfulfilled and inadequate as a result.

Often, families are aware of homosexual family members, but usually this is not discussed openly. The reality is that many Hispanic men who prefer sex with other men do marry and have children. This partly explains why Hispanics are at such high risk for **HIV**/AIDS. If the man has married and fathered a child, he has been congruent with the values relating to family; if he then goes out with men, or even with other women, this behavior may be tolerated as long as he continues to provide for his family. Figure 7-7 offers additional considerations for working with Hispanics.

#### Figure 7-7: Case Study: Heterosexual Minority Men Living With HIV

One recent study recruited 18 HIV-positive, heterosexual, minority men from an outpatient HIV/AIDS clinic in upstate New York and a community-based AIDS service organization in New York City to explore the experience of heterosexual minority men living with HIV. Findings revealed that the experience of surviving HIV infection encompassed several stages.

The participants in this study identified the choices they made in adolescence that led them down a hazardous pattern of behavior as the majority became involved in substance abuse or other illicit activities. With the diagnosis of HIV infection came a "falling off" stage, in which the participants went "over the edge" and initially were afraid to die but then realized that they were okay but vulnerable.

The next stage was "hanging on," in which study participants attempted to reassert control, reevaluated priorities, and developed a new perspective on life and health. In the "pulling up" stage, participants realized that the rescue team included self, God, family, and friends, with self-rescue taking place on emotional, physical, and spiritual levels.

As the participants reached the "turning around" stage, they began to accept responsibility for their health, focused on their abilities rather than their limitations, and began to see themselves as "living with HIV" rather than "dying from HIV."

Source: Sherman and Kirton, 1998.

## 5. African Americans

**HIV**/AIDS disproportionately affects African Americans, and from July 1998 through June 1999, injection drug use accounted for 26 percent of AIDS cases among African American males and 26 percent of cases among African American females (CDC, 1999b). (See Chapter 1 for more information about the epidemiology of the AIDS pandemic.)

African American women in particular have special needs. Minority women represent the fastest-growing segment of the U.S. **HIV**/AIDS pandemic. One study (Kalichman and Stevenson, 1997) examined the psychological and social factors related to **HIV** risk among 153 African American inner-city women. The women completed measures of **HIV** risk history, sexual and substance use behaviors, perceived risk for **HIV** infection, self-efficacy to reduce risk (i.e., the belief that one can effectively perform specific behaviors), and perceived social norms supporting risk reduction. Fifty-five percent of the women reported at least one factor that had placed them at known risk for **HIV** infection. Results showed that **HIV** risk history was associated with a self-perceived risk for **HIV** infection and low self-efficacy to perform risk-reducing actions, suggesting that **HIV** risk-reducing approaches to build self-efficacy and empower women to adopt risk-reducing practices (Kalichman and Stevenson, 1997).

Many African Americans have a deep-seated mistrust of the health system. This dates back to the pre-Civil War period when, because they were considered property and had no legal right to refuse, slaves were sometimes used in medical experiments (<u>Gamble, 1997</u>). A collective memory thus exists among the African American community of their exploitation by the medical establishment (<u>Gamble, 1997</u>). More recently, the syphilis study performed at Tuskegee University from 1932 to 1972, during which 400 African American men infected with syphilis were deliberately denied life-saving treatment, has fostered in some African Americans the belief that contact with health care institutions will automatically expose them to racist administrators and policies. Several articles point to the Tuskegee study as a significant factor in the low participation of African Americans in clinical trials and organ donation efforts and in the reluctance of many African Americans to seek routine preventive care (AIDS Weekly Plus, 1995; <u>Karkabi, 1994; Thomas and Quinn, 1991</u>). As one AIDS educator said, "so many African American people that I work with do not trust hospitals or any of the other community health care

service providers because of that Tuskegee experiment. It is like \_ if they did it once, then they will do it again" (<u>Thomas and Quinn, 1991</u>).

Counselors should be aware that the issues of slavery and institutional racism are constant and prevalent facts in the lives of many African Americans and should be addressed early in treatment so they are acknowledged, validated, and brought into the treatment process (CSAT, 1999A).

Spirituality is very important for many African Americans. The relationship between an individual and the faith community is a critical source of strength. In addition, many African Americans have strong social networks. Along these lines, for African Americans with substance use disorders and **HIV**/AIDS, support groups of friends may be more likely to be helpful and less undermining than support groups of families. This is perhaps due to the lingering stigma of the ways in which **HIV**/AIDS is acquired--both intravenous drug use and homosexual activity are still highly stigmatized acts within many African American communities. Thus, activating family supports may be difficult, and providers should encourage clients to participate in support groups composed of their peers.

#### 6. Asian Americans

Asians and Pacific Islanders are a culturally and linguistically diverse people from the Asian continent and the Pacific Islands. In the United States, they include nearly 40 different nationalities, 50 different ethnic groups, and more than 100 languages and dialects. Asians and Pacific Islanders comprised 4 percent of the total U.S. population in 1999. From July 1998 through June 1999, they accounted for 0.7 percent of all adult and adolescent **HIV** cases (these include only persons reported with **HIV** infection who have not developed AIDS), and 0.4 percent of adult and adolescent AIDS cases. Of the total AIDS cases reported for this population through December 1998, 89 percent were in men; 79 percent of those were reported in men who have sex with men (<u>CDC, 1999b</u>). Among women, nearly half the cases (48 percent) are associated with sex with an infected or high-risk partner, and 17 percent are reported from IDU (<u>CDC, 1999b</u>).

Service providers also should shed the notion of the "model minority," which often typecasts Asians and Pacific Islanders and limits treatment access. Often, Asians and Pacific Islanders believe the model minority myth and feel isolated when they test positive. They may also feel they have let down their families and communities.

By American standards, Asians and Pacific Islanders tend to communicate more indirectly, often by telling stories and discussing what happened to themselves and

others. Their feelings and opinions are implied rather than directly stated. Asians and Pacific Islanders are also less likely to provide direct verbal expression of their feelings by using "I" statements than are members of other groups. Providers should expect to reveal personal information about themselves if they want clients to disclose their own problems. Asians and Pacific Islanders may prefer to keep strong feelings under control so that they will not become disruptive. Caring is often demonstrated by physical support such as by giving money, cooking favorite foods, or giving advice rather than by verbal expression or physical affection.

A problem solving approach rather than an intrapsychic one is more effective with Asian and Pacific Islander clients. Problem solving enables a counselor to provide information, educational materials, and referrals without probing for more personal information and pushing a client to express feelings. For Asian and Pacific Islander clients with somatic complaints, suggest relaxation and breathing techniques, meditation, qigong, yoga, massage, acupuncture, tai chi, or biofeedback. It is generally not helpful to discuss underlying feelings because it is not only culturally unacceptable, but many Asian and Pacific Islander clients do not see the emotional-physical connection. In problem solving, providers should actively give suggestions and if necessary, be directive rather than let Asian and Pacific Islander clients struggle to figure out what options are available to them.

Asking personal questions about sexual risk factors, especially early in the helping relationship, could be viewed as intrusive and disrespectful. Asian and Pacific Islander clients may not answer truthfully, if at all, and may not return. It is best to start with the least intrusive or nonthreatening questions and explain why the information is needed. If clients seem uncomfortable with certain questions, ask them at a later date.

Making an effort to connect with clients outside actual treatment appointments via follow up calls is also helpful. Asian and Pacific Islander clients may not initiate contact when they have a problem because of cultural tendencies to minimize problems to reduce stigma and because they do not want to be intrusive and bothersome. In all interactions, it is helpful to minimize the stigma Asian and Pacific Islander clients attach to their **HIV**/AIDS status. Counselors should not refer to themselves as **HIV**/AIDS or mental health counselors unless they know the client is comfortable with this. These titles imply the client has an unacceptable condition and can increase stigma. Clients may be more receptive to treatment for **HIV**/AIDS if they are combined with other, less stigmatized health issues.

Group interventions can be effective if everyone speaks the same language well enough and if the group is centered around an un-stigmatized activity, social gathering, or education session. Providing refreshments also facilitates bonding. Asian and Pacific Islander participants will look to a facilitator to provide direction and guidance. Rather than be assertive in talking, Asian and Pacific Islander clients will more likely wait for a space to open up for them to speak and consequently will rarely have the opportunity to do so when in a group with predominately non-Asians and Pacific Islanders. Should this happen, the group leader needs to facilitate opportunities for Asian and Pacific Islander clients to participate.

## 7. Native Americans

Native Americans and Alaskan Natives comprised 0.9 percent of the total U.S. population in 1999. From July 1998 through June 1999, they accounted for 0.4 percent of all adult and adolescent **HIV** cases reported (these include only persons reported with **HIV** infection who have not developed AIDS) and 0.6 percent of adult and adolescent AIDS cases. The largest percentage of **HIV** and AIDS cases in women was from heterosexual contact (39 percent and 23 percent, respectively). The largest percentage of **HIV** and AIDS cases in men was reported in men who have sex with men (43 percent and 47 percent, respectively).

The CDC found that Native Americans have high rates of STDs and substance abuse, which in turn raise their risk of **HIV**/AIDS. They also lack access to diagnosis and treatment. Gay men and substance abusers run the highest risk of **HIV**/AIDS among Native Americans and Alaskan Natives, just as they do among white Americans.

The combination of high rates of cofactors for HIV/AIDS, limited access to health care, lack of information and education about HIV/AIDS issues, substantial numbers of Native Americans who are already infected with HIV, and the flow of Native Americans between urban centers and reservations all lead to an HIV/AIDS crisis for Native American communities.

In 1991, the American Indian Community House, which ministers to the health, social service, and cultural needs of Native Americans in the New York City area, created the **HIV**/AIDS Project, the first Native American program east of the Mississippi River to provide culturally sensitive legal services, **HIV**/AIDS treatment information, emergency assistance, and prevention education. The Friendship House Association of American Indians in San Francisco provides another example of treatment (drop-in centers). This program provides comprehensive treatment to Native Americans living with **HIV**/AIDS. Services target the gay, lesbian, and bisexual communities. **HIV**/AIDS is presently underreported for Native Americans and is based on the high incidence of sexually transmitted diseases (STDs) in general, and thus substance abuse treatment centers will be faced with more and more **HIV**-infected Native Americans.

## 8. Clients involved with the criminal justice system

Unfortunately, many **HIV**-infected individuals who are in treatment for **HIV** find it impossible to remain on their medication schedules after being arrested because their medications are often confiscated for days at a time.

The population in prisons and jails tripled between 1987 and 1997. Overcrowding and understaffing are common in prison facilities and can increase inmates' risk of contracting **HIV**. In 1992, **HIV**/AIDS cases for people in State and Federal prisons reached 195 per 100,000 compared with 18 per 100,000 for the general U.S. population.

Risky behaviors that lead to **HIV** infection are not eliminated when a person is imprisoned but may actually increase in frequency and availability. This occurs for several reasons. First, drug offenses count for the single largest number of Federal and State crimes for which people are arrested and incarcerated. In 1996, 79 percent of State inmates reported at least one use of illicit drugs during their lifetime. Therefore, high rates of **HIV** infection are not surprising in a population so closely characterized by heavy substance abuse involvement. In addition, many people enter jail or prison already infected with **HIV**. A 1993 study of 46 correctional facilities found people entering these facilities had an average infection rate of 1.7 percent. In some facilities, however, rates for women were as high as 21 percent and 15 percent for men. Among injection drug users, rates ranged from less than 1 percent to 43 percent.

Injection drug users face particular risk in prison settings as clean syringes are all but impossible to secure. Although syringes are not officially available, they can be acquired through illicit prison markets at exorbitant prices (\$34 in one Canadian facility) or through risky exchange of syringes for unprotected sex. Syringes are typically not new or sterile. As a result, injection drug users have as their only recourse used or shared syringes, which increases their chances of **HIV** infection. Tattooing is also common practice among prisoners and is another source of **HIV** infection. To date, there have been at least two documented cases of **HIV**/AIDS related to tattooing with unsterile needles in a correctional facility.

Only six prison systems in the United States distribute condoms: Mississippi, New York City, Philadelphia, San Francisco, Vermont, and the District of Columbia. Distribution strategies range from receipt of a single condom per medical visit to receipt of multiple condoms during **HIV**/AIDS education workshops. Furthermore, condom distribution programs send mixed messages because sexual activity in some facilities is illegal and a punishable offense. In other facilities, correctional

medical and social service staff may advocate condom availability while administration and security officers oppose it.

Sixteen prison systems mandate **HIV** testing, and although 77 percent make testing available to inmates on request, few inmates request it for several reasons. First, confidentiality of results is not guaranteed. Second, mandatory testing may result in the segregation of those who test positive from those who test negative or who do not test. Third, prisoners do not wish to acknowledge activities that could subject them to further sanctions. Fourth, confidentiality on discharge is eliminated because the Federal Bureau of Prisons requires **HIV** testing for all inmates on their release. **HIV**-positive inmates are asked to directly notify sex partners and significant others of the results. However, the Bureau of Prisons handles only a small percentage of inmates, and its policy is not the norm.

Treatment for **HIV**-positive inmates is often inadequate when available. Primary medical care may be limited to *Pneumocystis carinii* pneumonia prophylaxis and **HIV** monotherapy. Combination therapy may not be available or accessible to inmates, given the cost of medications, limited storage, refrigeration requirements for some medicines, and the strict adherence regimen required by combination therapy, which would require round-the-clock monitoring and assistance by typically unwilling and suspicious security staff.

Although there are large numbers of substance abusers within correctional facilities, less than 15 percent participate in treatment programs. This is partly because of lack of program availability and the common type of program offered (i.e., 12-Step, abstinence-based.) A 1991 study reported that only 1 percent of inmates with moderate to severe substance abuse disorders received appropriate treatment. Many of these treatment programs advocate sexual abstinence during recovery. Often, these programs offer no or little information about safer sex practices or advocacy around changing sexual behaviors. When persons with substance abuse disorders in treatment relapse, as is often the case, they may also engage in risky sexual behaviors. They are most likely to engage in risky sexual behaviors with sexual partners from similar treatment networks. These partners may include people who have used syringes, traded sex for money or drugs, or been victims of trauma. All of these populations are likely to have higher rates of **HIV** infection, making transmission likely.

## 9. Adolescents

Adolescents are another group that is experiencing an increase in incidence and prevalence of **HIV**. Since 1994, findings from the Monitoring the Future surveys have revealed a dramatic and sustained increase in consumption of licit and illicit

drugs among adolescents--this after nearly two decades of sustained decrease in drug consumption. Studies also note that teens are having sex earlier than ever before, often with multiple partners and inconsistent use of condoms, putting them at greater risk for **HIV**/AIDS. Beyond this, young people find themselves marginalized in U.S. society; this is especially true for young gay and bisexual youth, sexually active young women, and young people of color.

According to the CDC, AIDS is the fifth leading cause of death for Americans between the ages of 25 and 44 (CDC, 1999f). At greatest risk are young, disadvantaged females, particularly African American females, who are being infected with **HIV** at younger ages and higher rates than their male counterparts (<u>CDC, 1998j</u>). Because of the long and variable time between **HIV** infection and AIDS, surveillance of **HIV** infection provides a clearer picture of the pandemic in young people than surveillance of AIDS cases. From the States for which **HIV** is a reportable condition, young people ages 13 to 24 accounted for a much greater proportion of **HIV** than AIDS cases (17 percent versus 4 percent). Of these **HIV** infections, 38 percent were reported among young females, and 56 percent were among African Americans (<u>CDC, 1999b</u>).

#### **10.Older adults**

The last few years have witnessed greater increases in the number of **HIV**/AIDS cases among middle-aged and older individuals than in those under 40 years of age. Through June 1999, people over the age of 50 account for 11 percent of cumulative AIDS cases and 5 percent of cumulative **HIV** cases in the United States. Women comprise a greater percentage of all AIDS cases as age increases, ranging from 13 percent of AIDS cases among people aged 50-59, 15 percent of AIDS cases among those aged 60-69, and 21 percent of those 65 and over. For women with **HIV**, 22 percent of this group is in the 50-59 age bracket; 24 percent is aged 60-64; and 31 percent aged 65 and older. The rate of **HIV** infection in older women reflects the greater incidence of surgeries (such as hysterectomy) that require blood transfusions.

Although many of these AIDS cases are the result of **HIV** infection at a younger age, many people become infected after age 50. Rates of **HIV** infection among older adults are difficult to ascertain because very few people over 50 years of age routinely test for **HIV**. Because older adults are diagnosed with **HIV**/AIDS at advanced stages, older adults are less amenable to treatment, become sicker, and die faster than their under-50 counterparts. In addition, retroviral treatments and opportunistic infection prophylaxis may interact with medications the older person is taking to treat other preexisting chronic illnesses and conditions. Also, the vast

majority of medication studies are done on much younger subjects. There is little research on the metabolism of anti-**HIV** drugs in older adults.

Unfortunately, many medical professionals do not consider older patients to be at risk for **HIV** infection. A study in Texas found that most doctors never asked patients older than 50 years questions about substance abuse or **HIV**/AIDS or discussed risk factor reduction. Doctors were much more likely to rarely or never ask patients over 50 about **HIV**/AIDS risk factors (40 percent) than to rarely or never ask patients under 30 (7 percent). Older persons may not be comfortable disclosing their sexual behaviors to others, since their generation or culture may not encourage such disclosures. This can make finding treatment programs and support programs especially difficult.

Certainly, there is a need to educate service providers about the sex-related behaviors of older persons. At the very least, service providers should conduct thorough sex risk assessments with their patients over 50, and challenge all assumptions that older people do not engage in these activities or will not discuss them.

#### **11.Sex industry workers**

Among sex workers, street prostitutes are the most vulnerable to **HIV** infection, given the coexisting features of poverty, homelessness, history of childhood sexual abuse, and alcohol and drug dependence. Comparatively, male and female sex workers who work in massage parlors, escort services, their own apartments, or brothels rather than on the street are far less likely to be at risk for infection, less likely to depend on substances, and more likely to control sexual transactions and insist on condom use.

Seroprevalence rates among sex workers vary dramatically. A 1990 study of nearly 1,400 sex workers in six U.S. cities yielded a seroprevalence rate of 12 percent, ranging from 0 to 47 percent as a function of the city and the level of injection substance abuse. Most alarming was the high association of injection substance abuse and **HIV** infection rate.

Among female sex workers, IDU continues to be the major cause of **HIV** infection. Female injection drug users who trade sex for money or drugs are more likely to share syringes than injection drug users who do not exchange sex for money or drugs. Drug use also increases the likelihood of sex work and risky sex. Studies of crack cocaine abusers in three urban neighborhoods found that 68 percent of the women who were regular crack smokers exchanged sex for drugs or money. Of those, 30 percent had not used a condom in 30 days. Recent research has also demonstrated an association between **HIV** infection, heavy crack use, and unprotected fellatio. This is likely due to the combination of poor dental hygiene, damage to the mouth from hot crack stems or pipes, high frequency of fellatio, and inconsistent or marginal condom use. Street-based sex workers may agree to unprotected sex if clients offer more money, if workers themselves are desperate for money to buy drugs, or if activity has been slow.

**HIV** treatment challenges may occur given the sex workers' more immediate needs for drugs, food, and housing. These needs overshadow future concerns about living with **HIV**/AIDS. Beyond this, sex workers with **HIV**/AIDS may continue to work routinely for the purpose of exchanging sex for drugs or money. Sex workers thus run risks of spreading **HIV**/AIDS as well as reinfection of **HIV** and the acquisition and transmission of other diseases such as hepatitis and STDs.

## **12.Homeless people**

Homeless people suffer higher rates of many diseases, including **HIV**/AIDS than the general population. No national statistics exist, but studies within major U.S. cities are illustrative. In a 1993 study of homeless adults in Mississippi revealed that 70 percent of respondents engaged in at least one of the following high-risk behaviors: unprotected sex with multiple partners, injection substance abuse, sex with an infected partner, and exchanging unprotected sex for drugs or money. Of these respondents, nearly half reported two risk factors, and 25 percent reported three or four risk factors. Homeless people--especially women and youth--may engage in risky behaviors for survival reasons.

## K. Group Therapy Strategies

Consciousness-raising techniques in group may help when talking with a client who seems to lack basic information about behaviors or topics, such as **HIV** transmission. Questions such as the following can determine how much consciousness raising is needed:

- What are your concerns about HIV/AIDS?
- What do you think about "cleaning your works" in order to protect yourself?

Dramatic relief strategies can be used when talking with a client who knows something about topics like **HIV**/AIDS but still engages in unsafe behavior. Questions such as the following are helpful in determining the level of dramatic relief strategies:

• Do you feel you are at risk for HIV/AIDS?

• Do you worry about getting an STD?

Group therapy also can be used to present role models (peers) who have successfully addressed many of the issues clients may face. Peer programs can provide support for substance recovery and other psychosocial services. There are many resources in the community for these interventions; all a program must provide is a meeting place. It is helpful if the peer group facilitator has some training, even if this consists solely of the orientation that all substance abuse treatment program volunteers receive. Because they are not led by professionals, peer groups may be limited in what they can achieve. However, the absence of professional involvement may give peer groups greater credibility with hard-toreach clients.

Self-reevaluation (or self-reflection) and environmental reevaluation are good activities to use in group settings during inpatient treatment when clients might be motivated to change behavior. Self-reevaluation occurs when clients think about their behavior, and environmental reevaluation occurs when they think about the impact of their behavior on others. A counselor can initiate self-reevaluation by asking questions such as the following:

- Are there times you are willing to take risks by not using a condom? Why or why not?
- How often do you think about HIV/AIDS?
- Do you ever worry about getting something from your partner? What do you worry about? Why do you worry?
- Do you ever worry about giving something to your partner? What do you worry about? Why do you worry?

Environmental reevaluation can be facilitated with questions such as the following:

- How does your partner (partners) feel about using condoms?
- How would your partner (partners) feel if condoms were used?
- Do people close to you ever talk about HIV/AIDS? What do they say?

Group therapy can be very helpful in setting the stage for actual behavior change.

## 1. Stage of HIV infection

Segregating groups by stage of **HIV** infection presents difficulties, but not doing so can also be problematic. Clients who are **HIV** positive but asymptomatic and

attending a support group for the first time may be uncomfortable when encountering clients in the late stages of AIDS. Such a meeting may force them to confront fears about their own mortality before they are ready to do so.

Because treatment programs have limited resources, separating groups by stage of **HIV** infection may be impractical. Programs able to support separate groups may wish to use the three-group model, with groups consisting of

- Clients newly aware of their positive HIV status
- Those who are asymptomatic or mildly symptomatic
- Those with more advanced disease

In a group consisting solely of clients symptomatic with AIDS, members are vulnerable to becoming involved in a process of continual grieving. Sometimes groups have to discontinue for a period of time when too many members become sick or die. For this reason, it may be helpful to establish support groups for time-limited periods.

# L. Counseling Terminally Ill Clients

The counseling of ill and dying clients should be supportive and nonconfrontational, addressing issues relevant to the client's illness at a pace determined by the client. However, clients are not the only ones to be affected by the approach of death; counselors too may need assistance in dealing with clients' deaths. This section addresses the issues of denial, planning for death, pain management, unfinished business, and bereavement. A five-stage bereavement and loss model, based on Elisabeth Kübler-Ross' book *On Death and Dying*, also is presented.

## 1. Denial

Denial about a client's **HIV**/AIDS diagnosis can be experienced by both clients and counselors. Denial is a natural response and should be confronted only if it causes harm; for example, when a client in denial about his illness delays in making arrangements for medical and nursing care or procuring assistance with daily living activities. Counseling can play an important role in helping clients accept their illness and the eventual need for home health or hospice care.

Denial can also affect counselors. For example, because of the advances being made in the medical treatment of **HIV**/AIDS, a counselor may be in denial that a client will die of AIDS. Counselors must recognize and confront their own denial issues so that they are able to discuss death and dying and realistically explore

these issues with their clients. Programs need to have inservice education and proper supervision for counselors who work with terminally ill clients. Proper supervision will help the counselor confront her denial and help lessen her stress.

## 2. **Planning for death**

It is often difficult for a counselor to know how or when to talk to a client about planning for death. It is optimal, if possible, to begin a discussion of the client's future, including death, before the client is extremely ill. Questions that often lead the counselor into a discussion of death and dying, and also are centered on contingency planning, include, "if you were to become too ill to care for yourself any longer, what would you do, who would help, where would you go?" The counselor and client should also consider where the client would like to die because different arrangements may be required.

Counselors who will be working with clients at the end stages of AIDS should examine their own beliefs about death and dying. In addition to this, counselors may need to learn about the physical and biological process of dying so that it can be explained to clients. It is also important to keep in mind that clients' perspectives on death and dying are deeply rooted in their personal histories, religious practices, ethnic customs, family traditions, and community standards.

Many clients fear dying alone or in pain, or of losing control of their bodily functions, and thus having to rely on others for care. If clients want to talk about this personal and often frightening experience, the counselor should listen and help the client locate answers to any questions concerning the process of dying. Counselors should ask their clients how much they want to know and make sure that clients know what to expect physically. Understanding the process and planning the details within their power can give clients a sense of control.

In addition, clients may ask counselors to share their own beliefs about death and dying. Minimal sharing can be reassuring, but counselors should focus on the clients' perspectives, beliefs, and needs. As counselors listen, valuable information and insight into possible resources and support needed by clients will come to light.

## 3. Pain management

Pain management is often a difficult struggle with those who are in the end stages of AIDS. The issue of pain is complex because many medical conditions related to a client's **HIV**/AIDS can cause her pain. Another concern of clients is the appropriateness of pain management when it might hasten death. If a client raises

this issue, the counselor should be prepared to discuss it, however, the counselor does not initiate discussion on this topic. If the topic arises, clients should be encouraged to discuss pain management issues with their physicians and, if appropriate, their significant others.

### 4. Unfinished business

One important area that counselors should explore with their clients is "unfinished business." For example, a counselor might suggest that a client make a will. But there may remain other issues to be addressed. Should a client consider making an advance directive or a living will? Will the client want to appoint a health care proxy? Should he consider granting power of attorney to a significant other? Should he appoint a guardian for his children? Are there family issues that he wants to address?

Some counselors express a desire to be there at the time of a client's death, or a client may request that someone be there until death. Counselors and health care providers may also spend more time counseling the client's significant others or support people during this time than they spend counseling the client. Here again, a little information can go a long way to reduce fear and anxiety in clients and their significant others.

#### 5. Bereavement

Bereavement is a particular problem for programs with large numbers of **HIV**infected clients. Bereavement can affect clients (who may grieve at the deaths of other clients, friends, or loved ones from **HIV**/AIDS); clients' significant others; and counselors who work with dying clients. The following strategies may be helpful in supporting those clients who are dealing with bereavement.

- Acknowledge the reality of the bereavement in supportive individual counseling.
- Encourage the expression of grief both verbally and nonverbally (e.g., art therapy, expressive movement, psychodrama).
- Provide group support for clients and their significant others who are experiencing grief and bereavement.
- Acknowledge deaths with memorial services, flowers, photographs, and participation in commemorative projects such as The NAMES Project Foundation's AIDS Memorial Quilt, which attempts to include the names of everyone who has died of AIDS.

### 6. Kübler-Ross bereavement and loss model

One of the best and most often referred to models of bereavement and loss comes from physician and psychiatrist Elisabeth Kübler-Ross. In her book, *On Death and Dying*, she provides a five-stage theory that has become common language when dealing with death and dying. Her model of bereavement is essentially a series of defense mechanisms, or coping strategies, that are used by an individual confronted by death. These stages can also be observed as individuals are confronted with other traumatic circumstances or information, such as a positive **HIV** test, an **HIV**/AIDS diagnosis, or the death of a friend or peer. The five stages are denial, anger, bargaining, depression, and acceptance.

Individual interpretations of and responses to death and dying vary greatly, not only between people, but between cultures and religions. Yet, as this model eloquently describes, adjusting to death is a process, not an event that occurs seamlessly and in a logical sequential order.

The coping strategies and stages described below are not a recipe for health. Acceptance may not be the goal for everyone. Emotional processing is made more challenging when survival needs such as shelter, food, and medical care are not being met. Many clients are used to surviving with "street smarts" and not by psychoanalytical parameters and discussions about childhood. This model is included merely to help providers understand and relate to their experiences and their clients' experiences.

#### Denial

This is a time of terror management, an effort to psychologically buy some time while adjusting to the information or situation. It is here that people can feel the most isolated and the most suspicious and doubtful of the information that they are receiving. Denial is a natural and healthy response. It is not necessarily something that counselors must feel compelled to confront and rid clients of at the earliest possible moment. Allowing clients to have denial can be challenging, and for the caregivers and support staff it can be anxiety producing, but it is important to remember that above all else, this is the client's experience. Denial is not always negative. The times that denial must be confronted are when it causes a danger to self or others.

#### Anger

This stage emerges as the person accepts the diagnosis and begins to strike out. The most common targets for this anger are the people closest and safest to him, especially caregivers and service providers. Anger can also be a test. The person facing death may want to know who can be counted on as the end nears. This can sometimes be indirectly demonstrated by the client who may test the counselor's tolerance of anger; if the anger can be tolerated, perhaps the counselor can be trusted to tolerate the client's death and feelings of fear.

### Bargaining

Bargaining is the stage at which the individual commits to an uncommonly generous or humanitarian act with the belief that she will be spared or miraculously cured if deemed "good enough." The goal is a miraculous correction of the wrongs she has done, or possibly to buy some valuable time for treatment or dealing with end-of-life issues. The obvious danger is that most are not "cured" in that sense of the word, so what can happen is a loss of belief or faith.

## Depression

Depression represents a loss of denial, and an acknowledgment that the information is accurate and the situation and its consequences are unavoidable. As with clinical depression, the depth and severity depends on the specifics of the situation, mitigating factors, available resources, and the individual. This stage is marked by surrender to sadness; it is appropriate and adaptive. It is a time to collect resources and energies so that more processing can occur at a later time.

#### Acceptance

This is the stage in which some come to terms with their situation and feel a welcomed release from struggle and strife. Option formation and reality-based planning, given the circumstances, become the focus. Acceptance occurs when there is agreement between the physical body, the emotional heart, and the cognitive mind, that death will eventually be the outcome.

#### 7. No code or do-not-resuscitate orders

The responsibilities for determining when, how, and under what circumstances to evoke or effect no code or do-not-resuscitate (DNR) orders are properly the role of the family, or those with power of attorney, and the physician. The order itself comes from the physician or from the client through the physician. Although counselors do not initiate discussion of this topic, they should be aware of these terms and what they mean so that they can help prepare and inform the client and his family of these options. No code and DNR are terms used while a client is receiving care at an inpatient facility to identify a client who does not wish to receive medical intervention to save his life. For example, if a client has a DNR order and his heart stopped, he would not receive electric shock or cardiopulmonary resuscitation. It is the framing of these decisions and the terms used to help clients understand them that make all the difference. A counselor can help clients and their families talk about these concerns by first normalizing the process. That is, to present issues as no codes or DNRs, wills, and guardianship of minor children as decisions each person or family must come to grips with--whether they are ill or not, **HIV** positive or not. Counselors can approach and begin to discuss these issues within a context of "hoping for the best and planning for the worst." The discussion, then, is not related to being terminally ill, but rather to choosing, taking control, and making difficult, responsible decisions.

It also is helpful for the client or the family to discuss with the physician changing the goal of medical treatment. For example, at some point in the treatment process, when death is imminent and further aggressive medical intervention will be futile, the goal of treatment could be changed to "comfort care" from "no code."

Some States also permit a person who has been discharged from a hospital to home to have a DNR, which can be tacked to the door. The drawback of home DNRs is when a client dies and emergency medical personnel arrive, in most places they are required to try to revive the client. A counselor should be familiar with State laws about home DNRs so that a client who wants to die at home can be given the best information about this option.

Health care providers and counselors must maintain a sense of how their communication efforts are affecting the people they are trying to help. A specific and practical example of this is in discussions around no code or DNR orders. As health care providers discuss treatment options with clients and their significant others and the possibility of changing the goal of treatment to comfort care, one distinction that can be helpful for some people is the difference between "life support" and "death prolonging."

The current standard of care as defined by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) states that providers should develop a framework for decision making in situations that may require the withholding of resuscitative services or the foregoing or withdrawing of life-sustaining treatment. Decision making in such cases should reflect the following priorities (JCAHO, 1999):

- Enhancing the client's comfort and dignity by addressing treatment of primary and secondary symptoms
- Effectively managing pain
- Responding to the client's and his family's psychosocial, spiritual, and cultural needs

Many believe that decisions about medical treatment should not be based on "heroic" or "extraordinary" measures, or on medical complexity. They should be based on the potential outcomes and the benefits and burdens to clients and their support systems. An open and honest dialogue with the client, followed by a similar meeting with the entire care team, can facilitate decisions and move people to a place of comfort and resolution. Many States allow an individual to designate someone to serve as their "Durable Power of Attorney" for health care. Staff and clients should know what the State's regulations are.

### M. Assisting Clients in Preparing Their Children for the Loss of a Parent

It is estimated that the number of children orphaned by **HIV**/AIDS will increase by 200 percent in the next 20 years. Parents living with **HIV**/AIDS face a multitude of issues in preparing both seropositive and seronegative children for the loss of their parents. Fortunately, the child care system is developing credible guidelines on working with children with parents living with **HIV**/AIDS. In addition, placing a focus on providing for the future care and maintenance of the children can serve as a cause for personal motivation and empowerment. Pragmatically, clients should be assisted in preparing their children for the loss of parents in the following areas:

- Legal guardianship. Workers should help clients identify significant others or friends within the client system who could serve as legal guardians for their children. By stressing that children without legal guardianship become wards of the State, clients sometimes find the motivation to search for and secure guardians for their children.
- **Standby guardianship**. A standby guardian is someone who agrees to stand ready to assume guardianship (legal responsibility) for a minor when the parent of that child dies or becomes incapacitated. A parent will use the procedure when there is significant risk that he will die or become incapacitated within a certain period of time (e.g., in New York, this period is 2 years). The parent must usually petition a court for the appointment of a specific individual to be the standby guardian. The standby guardian can assume responsibility when the parent becomes incapacitated and then relinquish it when and if the parent recovers. The standby guardian's

authority is effective when she receives notification of the parent's incapacity or death.

- Leaving a legacy of living memories. An approach often used in agencies is working with parents to create living legacies for their children. For instance, families may be encouraged to make videotapes or audiotapes of themselves for their children. The National Hospice Organization has an excellent library of grief and bereavement materials, including some very good age-appropriate materials for children.
- **Dealing with survivor guilt.** The issue of survivor guilt is relevant for all family members but particularly so for the infected parent whose infant dies first. The problem of guilt must be brought forth, discussed, and processed so that clients can take a more proactive approach to their other problems.

### **Case Studies**

### Case Study 1

Frankie is a 21-year-old, self-admitted gay man. He has been injecting "crystal meth" off and on for 3 years. He has also been a chronic marijuana and alcohol abuser since he was 12 years old. He uses these substances particularly when he can't afford the "rig" and other drugs. He has sold his body for drugs but claims that he only has sex with "nice businessmen types." Frankie is new to the area and has been in town for about 9 months. He says his family does not approve of his lifestyle, so they made him leave home. He is in phone contact with his sister occasionally but only to let her know that he is "alive." Frankie lives in shelters and on the streets with other homeless adults and youth.

Frankie decides to enroll in an outpatient program because he has been hassled by the police lately and he went on a bad run using something called "fry" (marijuana soaked in formaldehyde, then smoked). He ended up in the emergency psychiatric unit at the county hospital and the staff there suggested that he seek some help. In addition, Frankie does know about **HIV**/AIDS and STDs and is concerned about his sexual behavior.

#### **Issues for the counselor**

## Referral and linkages

Frankie will need referrals for counseling and possibly testing for **HIV** and STDs if the facility does not provide these services. Referrals and linkages can be obtained

by getting Frankie's written consent if the facility is communicating with another organization about services for its clients. However, if an outside agency is providing services to the facility, then a Qualified Service Organizational Agreement (QSOA) (see Chapter 9 for more information about QSOAs) or Release of Information form will be required in order for the substance abuse treatment facility to be compliant with confidentiality laws. Frankie will also need a risk assessment to help him determine just what his risks are and risk-reduction counseling regardless of his decision about any medical testing.

## Special population/cultural competency

The fact that Frankie is gay could be a concern if the treatment facility has not dealt with members of the gay population or has difficulty in dealing with this population. It will be important that Frankie is assigned to a counselor who is nonjudgmental and has had some experience with young gay men.

## Relapse

With Frankie, it may not be an issue of relapse as much as getting Frankie to discontinue or cut down his use. He is currently motivated for treatment but this "scare" may not last. A risk reduction model may work best with Frankie as this appears to be his first attempt at treatment and total abstinence may be unrealistic. This should be explored further with Frankie.

## Denial/anger

Although Frankie may not have shown any of these emotions yet, they probably should be explored with him (as well as others, such as depression, grief, loss) specifically as it relates to his family and their treatment of him, as well as his having to survive on the streets.

## Medical complications

There may be a need to further examine Frankie if he does not stop using fry or other substances. The medical complications to the heart, kidneys, lungs, and brain would be worse if he has **HIV**/AIDS or any other STDs. Because he has been on the streets, he probably has not seen a doctor for anything until he ended up in the emergency room.

#### Case Study 2

Tina is a 29-year-old African American female. She has been using marijuana and alcohol since she was a teenager and progressed to using cocaine by her early 20s. Tina reports snorting cocaine for a couple of years when working as a dancer. She then discovered crack, which has been her drug of choice for the last 6 years.

Tina has been in and out of jail several times over the past few years, usually on prostitution charges. While in jail, she always tests for STDs and HIV/AIDS. She has repeatedly tested positive for chlamydia and has received treatment numerous times. Despite the treatments for the STD, she continues to test positive. During her most recent incarceration she was diagnosed with pelvic inflammatory disease, had an abnormal Pap smear, and tested positive for HIV. Other than being a little underweight she looks good and states that she feels fine with the exception of some abdominal pain.

Tina is very excited about her "new life" with her boyfriend, by whom she has been trying to become pregnant. Having **HIV**/AIDS does not seem to be a major concern for Tina because she knows that there is medication out there for the disease. She reports that she was already getting off drugs before the bust because she wants to get married and have a baby now that she's found the right man. She reports her main support to be her boyfriend of 2 months. She does have a couple of female friends but does not consider them close.

She has been court ordered to go to substance abuse treatment. She has made several treatment attempts before and states she doesn't understand why she has to go to treatment now when she was already planning to stop her drug use voluntarily. She is now being admitted to a 30-day inpatient treatment program; otherwise, she faces going to jail for a minimum of 1 year.

#### Issues for the counselor

#### Relapse

This is the main area of concern. Tina has a long history of substance abuse. She reports little to no social support for her recovery. The nature of crack addiction suggests that a 30-day inpatient setting will "only be the beginning" of the treatment episode. The connection and consequences of high-risk activities need to be discussed and risk-reduction practices demonstrated and rehearsed. It appears that Tina is clearly in denial about her addiction and diseases and does not understand treatment and recovery. This may be exhibited through her either

becoming a "compliant client" just to get along or a defiant, angry client because she doesn't think she needs treatment.

#### Medical

Tina has a number of medical issues that must be addressed and further explored. Tests and treatment for recurrent STDs, pelvic inflammatory disease, abnormal Pap smear, andHIV/AIDS are needed. With further exploration cervical cancer may be revealed, which could, in turn, give her an AIDS diagnosis. A pregnancy test may also be needed. The counselor needs to remember that it is Tina's decision about the issue of pregnancy. A counselor should watch for the issues relating to **HIV**/AIDS and pregnancy that can arise.

### **Referrals and linkages**

Tina will need medical referrals. She has so many issues in this area she would benefit by having an **HIV**/AIDS case manager to assist her in linking with and coordinating appointments, medication, and so on. She may also need all the "standard" services such as housing, transportation, and clothing.

### Compliance

There could be some compliance issues with this client. This is indicated by the good possibility that she was not taking her STD medication as directed and her statement that she doesn't understand why she has to go to treatment. This belief should be explored further because it could be a lack of information/education and not a compliance issue at all.

## The Author

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