

# WHAT DO I DO?

A HANDBOOK TO  
UNDERSTANDING  
HEALTH AND HIV

BY



HUMAN  
RIGHTS  
CAMPAIGN  
FOUNDATION™

AIDS  
United 



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# Introduction



**1 IN 7 DOESN'T KNOW THEIR  
HIV STATUS**

**40,000**

**NEW DIAGNOSES  
EACH YEAR**



**1 IN 5 CASES OCCUR AMONG  
YOUTH BETWEEN AGES 13-24**

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Of the 1.2 million people living with HIV in the United States, roughly one in seven does not know their HIV status. Approximately 40,000 people are diagnosed with HIV each year, with one in five cases occurring among youth between the ages of 13 and 24. Gay and bisexual men and transgender women, particularly of color, continue to bear the biggest burden.

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Why, as we make extraordinary progress in the fight for lesbian, gay, bisexual, transgender, and queer (LGBTQ) equality, are we still dealing with staggering rates of HIV? Misinformation, persistent stigma and societal barriers such as discrimination and poverty are some of the main causes. Additionally, many people simply haven't kept up with the current realities of HIV and AIDS.

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**The purpose of this handbook is to provide accurate and actionable information about HIV prevention, treatment and care.**

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In Part One, we provide a simple, yet comprehensive, overview of HIV and the ways it's transmitted. In Part Two, we focus on HIV testing and the importance of knowing your status. In Part Three, we discuss the meanings of an HIV test result and what to expect depending on the outcome. In Part Four, we offer guidance on how to prioritize your sexual health in a way that's sex-positive and shame-free.

Each part includes a section entitled *Know Your Facts — Debunk the Myths*, which was created to tackle common misconceptions about HIV and AIDS. Make sure to check them out! Finally, you can find a glossary of key terms and additional resources near the end of the guide.

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**This handbook will only be effective with your active participation.**

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Help us dismantle the stigma surrounding HIV, promote safer sex and maintain an open and honest dialogue by reading this handbook and sharing it with your sexual partners, loved ones, friends, family and social networks. HIV is a community issue that requires a shared response and sustained contribution from all of us — no matter your HIV status.

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**And remember, this is just one resource guide. It's not a substitute for sound medical advice — and the examples in it don't cover every situation!**

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We encourage you to seek out additional resources from other community advocates, and most importantly talk to a knowledgeable healthcare provider before making any medical decisions.

**Regardless of your HIV status, we all have a responsibility to learn, to share and to act.**



# 1

## **PART** **ONE**

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# Let's Start with the Basics!



## **HIV is a virus.**

HIV works by attacking your body's immune system, which is crucial to fighting off infections and diseases. If ignored, HIV can lead to an **AIDS diagnosis**.



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HIV can hide in your body without producing recognizable symptoms. However, that doesn't mean the virus isn't damaging your health. The only way to know if you have HIV is to get tested (see Part Two).

Your body cannot get rid of HIV by itself. Fortunately, there are now several ways to prevent and treat HIV.

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And with the help of a knowledgeable healthcare provider, you can lead a long, healthy life, regardless of your HIV status (see Parts Three and Four).



# Stages of HIV

## 1

### EXPOSURE

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- HIV enters the body.

## 2

### PRIMARY/ACUTE

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- Some people, **but not all people**, experience flu-like symptoms.
- If symptoms do occur, they usually start within two to four weeks of HIV entering the body.
- These flu-like symptoms are the body's natural response to HIV. However, it's important to keep in mind that many illnesses can cause flu-like symptoms.
- The only way to know if you've been exposed to HIV is to get tested.

# 3

## LATENT

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- People in this stage don't have any noticeable symptoms even though the virus is slowly making copies of itself.
- People in this stage **who know their HIV status** and consistently take their medication will remain in good health as they lower the amount of HIV in their bodies to undetectable levels.
- People in this stage **who don't know their HIV status**, or who don't take their medication consistently, will likely stay in this stage for a period of time before moving onto the most serious stage of HIV.

# 4

## AIDS

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- People living with HIV who don't consistently take their medication will likely advance to this stage of HIV. At this stage, the body isn't as able to fight off diseases.
- Because HIV severely weakens the body's immune system, other illnesses may soon appear. Even something like a common cold can cause serious problems in this stage of an HIV infection. These types of illnesses are called "opportunistic infections," which affect individuals with weakened immune systems more seriously and frequently than others.
- Fortunately, people living with HIV can avoid getting to this stage if they know their status, see a knowledgeable healthcare provider and consistently take their medication.

# How Do People Get HIV?

HIV is transmitted through the following bodily fluids:

- **Blood**
- **Semen** (i.e., cum)
- **Pre-seminal fluid** (i.e., pre-cum)
- **Vaginal fluid**
- **Rectal fluid**
- **Breast milk**



**It's important to know that you cannot get HIV from kissing, hugging or other types of non-sexual physical contact.**

# Routes of Transmission

While HIV can be transmitted at any stage, it is most commonly transmitted by people who are unaware of their HIV status or who are not connected to care. It is virtually impossible for someone living with HIV to pass the virus onto someone else once they've consistently taken their medication and maintained an undetectable viral load for at least six months.<sup>2</sup>

For transmission to occur, bodily fluids from a person living with HIV must enter the body of a person who is HIV-negative. Following are several ways for this to happen:

Most commonly, HIV is transmitted through **condomless anal or vaginal sex**.<sup>1</sup> In general:

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**HIGH RISK** Condomless anal sex (e.g., barebacking) is considered the highest-risk sexual activity followed closely by condomless vaginal sex.

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Receptive partners (e.g., bottoms) are more susceptible to contracting HIV than insertive partners (e.g., tops).

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**LOW RISK** While condomless oral sex is considered a low-risk sexual activity, transmission can occur. Also, keep in mind that oral sex includes any activity that involves using the mouth on the penis, vagina or anus (i.e., rimming). And the risks increase after flossing, brushing or anything that could irritate the gums.

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**1** In this handbook, the term "condomless sex" refers to sex without condoms or the daily use of HIV medications prior to exposure (i.e., PrEP).

**2** In this handbook, the term "undetectable" refers to what happens when the amount of HIV in a person's body cannot be detected by standard HIV tests (i.e., undetectable viral load).

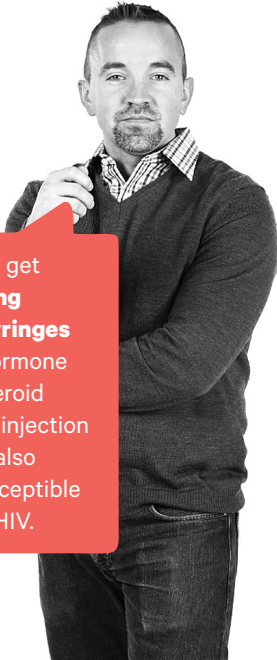
# FAST FACTS:

## ABOUT HIV AND SEX:

- Having another sexually transmitted infection (STI), such as syphilis or genital herpes, may increase your chances of contracting HIV. Therefore, it is important to **get tested regularly for other STIs** in addition to HIV.

- The best way to protect yourself from HIV and other STIs is to use a combination of **safer sex practices**, including condoms and PrEP.

- While undetectable, a person living with HIV **remains in good health** and it is virtually impossible for them to transmit the virus to a partner.



People can also get HIV from **sharing needles and syringes** for drug use, hormone injections or steroid injections. Non-injection drug users are also particularly susceptible to contracting HIV.

# FAST FACTS:

## ABOUT INJECTIONS AND HIV:

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- **Sharing your hormone, steroid or insulin bottle** with other people may increase the chances of HIV transmission even if you use your own needle.
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- **Using equipment** such as “cookers” and “filters” with other people may increase the chances of HIV transmission even if you don’t share needles or syringes.
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## Less commonly, HIV may be transmitted by:

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- Being born to a mother with HIV. HIV can be passed **from mother to child** during pregnancy, birth or breastfeeding.
  - Being pricked by a **needle or other sharp object** that has been used on or by someone living with HIV.
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# Know Your Facts — Debunk the Myths

The scientific community and the American public have learned a great deal about HIV and AIDS since the 1980s. However, several misconceptions persist. Not only do these myths stigmatize people living with HIV, they often discourage people from getting tested or treated in the first place. Look for this section throughout the guide as we tackle common myths about HIV and AIDS. And be sure to share this information with friends, family, loved ones and sexual partners. Know your facts — debunk the myths.

## MYTH:

**“No matter what they say, HIV is a death sentence.”**

## FACT:

HIV is an easily treatable long-term medical condition that can cause serious problems if left ignored. With recent advances in HIV treatment, it is entirely possible for people living with HIV to lead long, healthy lives by seeing a knowledgeable healthcare provider and consistently taking their medication.



## MYTH:

**“Let’s be honest, HIV is only a problem for gay men, transgender women and heroin addicts. Only ‘those people’ are at risk.”**

## FACT:

HIV doesn’t care about who you are. HIV cares about what you do. Anyone — regardless of race, sexual orientation, gender identity or ability status — can acquire HIV if they engage in behaviors that are likely to transmit the virus.

## MYTH:

**“I can tell whether someone is HIV-positive just by looking at that person.”**

## FACT:

Some people can live with HIV for more than 10 years without showing signs or symptoms. No matter what people say, there's no way to know whether someone is (or isn't) living with HIV just by looking at them.

# Takeaway Points

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HIV is an **easily treatable, long-term** medical condition that can cause **serious problems** if left ignored.



While undetectable, a person living with HIV **remains in good health** and it is virtually impossible for them to transmit HIV to someone else.

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HIV **can be treated** by seeing a knowledgeable healthcare provider and consistently taking **HIV medication**.



The only way to know if you have HIV is to

**GET  
TESTED.**

# 2

## **PART** **TWO**

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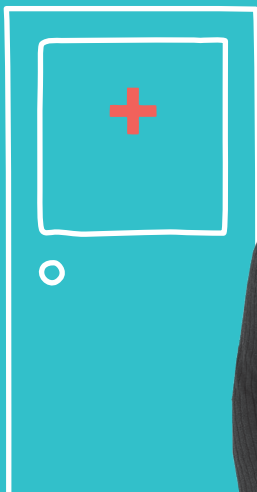
# Know Your Status

Ever since the creation of the first HIV test in 1985, public health officials have repeated one message over and over again: **Know your HIV status.** HIV testing is a powerful prevention tool — and can be done at doctors' offices, at community organizations or even through at-home tests.<sup>2</sup>

## WHY IS IT IMPORTANT TO KNOW YOUR STATUS?

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- It gives you peace of mind.
- It gives you the benefit of early treatment.
- It helps prevent the spread of HIV.



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**2** Be sure to visit [locator.aids.gov](https://locator.aids.gov) to find a free or low-cost HIV testing or treatment site near you.

## WHO SHOULD GET TESTED FOR HIV?

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The Centers for Disease Control and Prevention (CDC) recommend that everyone between the ages of 13 and 64 get tested for HIV at least once as part of routine healthcare, and that some people get tested more often. For example, gay and bisexual men and transgender women should consider getting tested for HIV and other STIs every three to six months, as HIV is more prevalent in these communities. The majority of adults in the United States who never get tested say it is because they do not think they are likely to contract HIV. However, consider the following scenarios.

### HAVE YOU EVER...

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- Had condomless vaginal, anal or oral sex?
- Had condomless vaginal, anal or oral sex with someone you just met — for example, on the Internet or through a mobile-based app such as Grindr?
- Had condomless vaginal, anal or oral sex with someone whose HIV status you didn't know?
- Exchanged sex for drugs, money, housing or food?
- Tested positive for an STI, hepatitis or tuberculosis?
- Shared needles or injection equipment with other people?
- Had condomless vaginal, anal or oral sex with people who may have engaged in any of the behaviors listed above?

**If you answered "yes" to any of these questions, then you should consider getting tested for HIV.**

# Understanding the Window Period

The window period is the length of time it takes for an HIV test to detect whether transmission has occurred. The time it takes to detect HIV varies from test to test and slightly from person to person.

Testing for HIV during a window period can lead to a false test result, especially if you engaged in high-risk behaviors in the weeks or months leading up to your test. That said, if you think you've recently been exposed to HIV, it's important to see a doctor or healthcare provider as soon as possible. There are medications you can take immediately after exposure to reduce your risk of contracting HIV (see Part Four).

## CONSIDER THE FOLLOWING SCENARIO:

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- Today you get an HIV-negative test result.
  - Your doctor used a test with a three-month window period.
  - Meaning of the result: You were more than likely HIV-negative three months ago.
-

## AT THE END OF THE DAY:

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- If you test negative for HIV but continue to engage in high-risk behaviors, you should repeat the test periodically.
  - Ask a knowledgeable healthcare provider or HIV test counselor about the window period of your HIV test and what it means for you.
  - Your HIV test result expires every time you engage in high-risk behavior.
- 



# Know Your Facts — Debunk the Myths

## MYTH:

**“I am over 50!  
I don’t need to  
worry about  
HIV.”**

## FACT:

Remember, HIV transmission is about behavior, not how old you are. Moreover, older Americans are more likely to be diagnosed with HIV at a later stage of the disease.

## MYTH:

**“I am  
monogamous.  
I don’t have to  
worry about  
HIV.”**

## FACT:

It is still important to get tested for HIV even if you’re in a monogamous relationship. According to the latest estimates, 68 percent of new HIV transmissions among gay and bisexual men occur in the context of a primary relationship (e.g. boyfriend, friend with benefits). It is incredibly important to talk openly and honestly with your partner about your sexual health and practices. You might consider getting tested together for HIV and other STIs.



## MYTH:

**“I see my doctor every year for a full physical. I am sure the HIV test is included.”**

## FACT:

HIV screenings should be a routine part of your annual exam, but it may not always happen this way. Be sure to ask your healthcare provider about it just to be safe. People who are especially susceptible to contracting HIV should consider getting tested every three to six months. Talk to your doctor or provider!

## MYTH:

**“I tested negative for HIV. I don’t have anything to worry about.”**

## FACT:

Testing for HIV during a window period can lead to a false test result, especially if you engaged in high-risk behaviors in the weeks or months leading up to your test. Be sure to get tested early and often!

# Takeaway Points

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**Everyone**, starting at age

13

should consider getting

**TESTED**

for HIV at least once as part of routine healthcare. Some people, including gay and bisexual men and transgender women, should consider getting tested more often.

**Early detection** of an HIV infection is important to benefit from early treatment and prevent passing the virus onto others.



Be mindful of the

**WINDOW PERIOD**

which can **vary from test to test.**

## What's Next?

Your HIV test came back positive. What's next?

Your HIV test came back negative. What's next?

# 3

## **PART** **THREE**

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# Getting the Result

There are many different types of HIV tests, and they can be based on anything from an oral swab to a finger prick to a standard blood draw. And depending on the test, your result could be ready in as little as 20 minutes or less.

Regardless of the type of test you take, it's a good idea to learn **what happens next** regardless of the outcome.



**Your test result can be negative, inconclusive or positive.**



# Negative Result



## WHAT DOES IT MEAN?

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The test did not find signs of HIV in your body. If it has been at least three to six months since you last engaged in high-risk behaviors (see Part Two), then you probably do not have HIV.

## WHAT DO I DO NOW?

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You have two important tasks: Remain HIV-negative and consider additional prevention strategies.

- Be mindful of the ways HIV is transmitted and get tested regularly.
- Talk to someone you trust — whether that's a knowledgeable healthcare provider or a community educator — to determine the strategy, or the combination of strategies, that makes the most sense for you (see Part Four).

## WHAT SHOULD I EXPECT?

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Some people experience stress related to safer sex practices. Using a mix of strategies may result in more pleasurable and stress-free sex.

# Inconclusive Result



## WHAT DOES IT MEAN?

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Sometimes the test result is neither positive or negative. This situation can occur for any number of reasons, including a flawed HIV test or human error.

## WHAT DO I DO NOW?

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An inconclusive HIV test can cause stress and anxiety. Try to stay calm and be patient, as your doctor or HIV test counselor will likely order additional testing to determine your HIV status. It is very important to follow your healthcare provider's instructions during this time to exclude the possibility of missing an early HIV infection.

## WHAT CHALLENGES SHOULD I EXPECT?

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Your healthcare provider will tell you if and when further blood samples are needed. It is your responsibility to come back for follow-up testing.

# Positive Result



## WHAT DOES IT MEAN?

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A positive test result should always be followed by a confirmatory test. If this second test is also positive, it means HIV is in your body.

## WHAT DO I DO NOW?

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Many people don't get tested for HIV just to avoid the possibility of receiving this news. But you took the first step, which is hugely important and gives you the opportunity to get connected to care sooner rather than later so you can benefit from early treatment.

While HIV is now an easily treatable long-term medical condition, many people who receive an HIV-positive diagnosis report feeling confused, isolated and scared. These are natural responses and can be difficult to manage. But remember, HIV is nothing to be ashamed of. Many people living with HIV are able to lead long, healthy lives with proper medical care and the support of loved ones.

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**Here are some things to keep in mind:**

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**Time.** It's OK to take some time to deal with the diagnosis and to sift through your emotions. An HIV-positive test result is not always an easy thing to accept. Feel free to take a few days for yourself if it will help you respond more effectively.

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**Doctor.** Find a doctor or licensed healthcare provider in your area who has experience treating people living with HIV. You should schedule a medical visit with that person within two weeks of your HIV-positive test result. The person who tested you should be able to provide you with a list of referrals. You can also use the Internet. If you don't like the provider referred to you, that's OK — you will be able to switch in the future. However, you should take any opportunity to see someone right away.

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**Insurance.** If you are uninsured, underinsured or undocumented, tell that to the person who tested you. There are programs that can provide free or subsidized health insurance for people living with HIV, regardless of their immigration status.

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**Information.** The more you know about HIV, the easier it will be to manage your diagnosis. Read books and brochures, talk to HIV counselors and health educators, follow treatment news and updates and connect to organizations promoting HIV awareness on social media such as TheBody.Com, AIDSmeds, Greater Than AIDS and AIDSMap.

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**Check-ups.** Monitor your body. Your doctor will order periodic lab work to check how your immune system is doing and to see if it's keeping the virus in check. Get familiar with the meaning of your lab results and do not miss regular check-ups.

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## 6

**Support.** Find support from trustworthy friends, family members and loved ones. Ask the person who tested you to provide you with referrals to therapists, social workers, case managers and support groups for people living with HIV. There are plenty of resources out there. Again, consider using the Internet to help you make these important connections.

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## 7

**Drugs.** If you believe drugs were a factor that may have led to your HIV diagnosis, tell that to the person who tested you or your case manager. That person can likely connect you to social support services that will help you address the issue if you're ready. Keep in mind that addressing substance abuse issues will only lead to better health outcomes in the long run.

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## **There are at least two things you must continue doing to maintain a long and healthy life with HIV:**

- See your doctor regularly
- Take your medication as prescribed

The main goal of HIV treatment is to keep the amount of HIV in your body (i.e., viral load) to undetectable levels. Research shows that having an undetectable viral load enables people to lead longer, healthier lives and virtually eliminate the chances of transmitting HIV to someone else.

## **WHAT CHALLENGES CAN I EXPECT?**

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Connecting with a doctor or knowledgeable healthcare provider will go a long way toward helping you mitigate any of the health-related challenges that come from living with HIV.

# Disclosing Your HIV Status

Open, safe and honest communication about your HIV status, whether positive, negative or unknown, is crucial to maintaining personal and community health.

Disclosure — the act of telling someone about your HIV status — often promotes intimacy as well as safety.



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While a lot of great things can happen by disclosing your HIV status, the lingering stigma that surrounds HIV can lead to problematic situations.<sup>3</sup> This is particularly true if you live in a state where HIV disclosure is mandated by law.<sup>4</sup>

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## **FACTORS THAT MAY AFFECT DISCLOSURE:**

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### **1. Who.**

Think about the different kinds of relationships you have with people before deciding whom to tell. Consider what good would come from disclosing your HIV status to that particular person. Generally, it is recommended that you disclose to people who are close to you and can provide you with love, support and understanding.



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**3** Under the Americans with Disabilities Act (ADA), HIV and AIDS qualify as disabilities, even if asymptomatic, and employers are prohibited from discriminating on either basis. Be sure to contact the nearest Equal Employment Opportunity Commission (EEOC) office ([www.eeoc.gov](http://www.eeoc.gov)) within 180 days of a discriminatory event.

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## 2. When.

Avoid disclosing in the “heat of the moment” — for example, when you are angry, upset or if you are not feeling well. Disclosure is a personal journey that sometimes may include roadblocks. It’s best to approach disclosing your HIV status with love, support and understanding.

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## 3. Where.

Be mindful of your surroundings. In general, it’s best to disclose in a calm, intimate space that allows you to express your feelings and show your emotions. However, if you fear someone may react violently, you may want to go to a public place.

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## 4. How.

There isn’t one best practice for telling someone about your HIV status. Someone on your medical team should be able to connect you to support groups that can help you learn communication skills for this precise task. You also may be able to practice with your doctor or with a friend who already knows your status.

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## 5. Why.

There are several reasons why it might be worthwhile to disclose your HIV status to someone:

- To give previous and current sexual partners the chance to get tested
- To reduce the risk of transmission
- To obtain support
- To access medical care
- To obey laws<sup>4</sup>
- To fight stigma

**Ultimately, deciding whom to disclose your HIV status to (and when) is a very personal decision and part of an ongoing process that develops over time.**

<sup>4</sup> More than 30 states have laws in place that make it illegal to withhold your HIV status from a potential sexual partner. Many of these laws include references to behaviors that cannot transmit the virus, such as spitting or biting. There is no proof that these laws work, and they run counter to public health. That said, you should seek legal counsel immediately if you have been accused of “infecting someone with HIV.” Visit the Sero Project ([www.seroproject.com](http://www.seroproject.com)) or Lambda Legal ([www.lambdalegal.org](http://www.lambdalegal.org)) for more on HIV criminalization.

# Know Your Facts — Debunk the Myths

## MYTH:

**“HIV drugs are poison. They will destroy your body.”**

## FACT:

At the beginning of the AIDS epidemic, HIV medications were difficult to take and had debilitating side effects. Since then, scientists have created medications that have fewer side effects and are easier and safer to use.

## MYTH:

**“I am not worried about HIV. I read online that scientists are very close to finding a cure.”**

## FACT:

There is currently no cure or vaccine for HIV.

# Takeaway Points

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**Know your status**  
and respond accordingly.



If **you're HIV-negative**,  
stay that way and

## **ADOPT STRATEGIES**

to prevent HIV in the  
future.

If you are **HIV-positive**,  
**stay optimistic**. Your  
doctors and their teams,  
in collaboration with  
great treatment options,  
can help you lead a long,  
healthy life.



Take your HIV medications  
every day as prescribed  
and **stay connected  
to care**.



## **What's Next?**

Sexual health  
Condom use  
PEP and PrEP



# **PART** **FOUR**

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# Sex, Sexuality and Sexual Health

**Sex should be fun! It should be a pleasurable and stress-free experience.**

**A crucial part of having enjoyable sex is maintaining your sexual health.**






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Sexual health refers to your physical, emotional and mental well-being as it relates to your sexuality. Often people only think of sexual health in negative terms (e.g., avoiding STIs). But it's so much more than that!

Sexual health means that every person should be able to have safe, pleasurable and consensual sex free of negative feelings, violence or coercion.

One way to keep your sexual health in tip-top shape is to choose safer sex strategies that work for you and your sexual partners. You should choose safer sex strategies that enable you to embark on a healthy and fun sexual journey while minimizing the spread of HIV and other STIs.



**All of us should be mindful of our sexual health, regardless of HIV status.**

**There are at least two kinds of safer sex strategies that can minimize the spread of HIV.**

# 1

## **BEHAVIOR-BASED PREVENTION STRATEGIES.**

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These safer sex strategies are meant to lower the risk of acquiring or transmitting HIV by preparing people to deal with challenging situations. They include:

- Sexual health education
  - Condom negotiation
  - Risk-reduction counseling
  - Disclosure
- 

# 2

## **MEDICINE-BASED PREVENTION STRATEGIES.**

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These safer sex strategies involve taking HIV medications before or after exposure to reduce the risk of getting or transmitting HIV. They include:

- Post-exposure prophylaxis (i.e., PEP)
  - Pre-exposure prophylaxis (i.e., PrEP)
  - Treatment as prevention (i.e., “dating undetectable”)
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# Behavior-Based Prevention Strategies

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## Condoms

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The consistent and correct use of condoms and other latex barriers (e.g., dental dams, finger cots, latex gloves) is a proven and cost-effective way of preventing the spread of HIV and other STIs. Condoms come in many shapes, sizes, colors and flavors. They are widely available and are often free of charge at LGBT centers, bars and clubs.

Condoms should be used correctly during every sexual encounter for maximum protection. If you find it difficult to use condoms correctly and consistently, think about adding other safer sex strategies such as PrEP.



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## Other Behavior-Based Prevention Strategies

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### 1

#### **Use lube.**

Use abundant amounts of water-based or silicone-based lubricants, especially during anal sex. Avoid using oil-based lube such as Vaseline or baby oil as it can damage condoms. Often body parts are not lubricated enough for penetration which can cause tissues to tear, thereby facilitating the spread of many STIs including HIV. Always consider using lube for vaginal and anal sex.

### 2

#### **Be mindful of drugs and alcohol use.**

Alcohol and drugs can facilitate the spread of HIV directly, by needle sharing, or indirectly, by causing people to use sex as a way to support their addiction or by impairing their judgment. If you believe that your use of alcohol and drugs is problematic, consider having a candid conversation with your doctor, a counselor or a therapist.

### 3

#### **Change syringes.**

If you inject hormones, drugs or steroids, consider using your own clean syringe and other injection equipment. See the “Additional Resources” section to find a clean syringe exchange program near you.

### 4

#### **Test and treat STIs.**

Having an active STI, or even a history of STIs, can make you more susceptible to contracting HIV. Get tested regularly if you are sexually active and make sure to get treated immediately if you test positive for an STI.

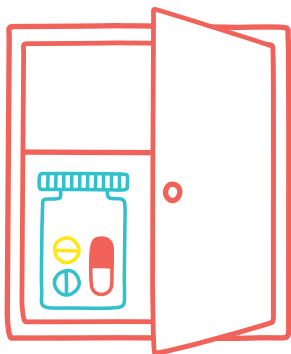
# Medicine-Based Prevention Strategies

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## Pre-Exposure Prophylaxis (PrEP)

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PrEP is short for pre-exposure prophylaxis. It is an HIV prevention strategy that currently involves taking a once-daily pill to reduce the chances of acquiring HIV. As of publication, the only pill that is FDA-approved for PrEP is a prescription medication sold under the brand name Truvada®. People who use PrEP must commit to taking the drug every day and seeing their healthcare provider for follow-up and additional testing every three months.



PrEP is intended for HIV-negative people, especially those who may be in an ongoing relationship with a person living with HIV, does not consistently use a condom when having sex, or shares injection drug or hormone equipment.

# FAST FACTS:

## ABOUT PREP

- PrEP **is safe** and highly effective when taken as prescribed by a knowledgeable healthcare provider.
- Anytime you start PrEP, remember that it takes at least **seven days** of daily use to provide maximum protection during anal sex. Wait at least 21 days for vaginal sex.
- As of publication, **Truvada** is the only HIV medication that is FDA-approved for PrEP. The pill has to be taken **every day** for it to be most effective.
- PrEP users should continue **using condoms** while on PrEP, as they provide an additional layer of protection against STIs and unwanted pregnancy.
- PrEP can only be prescribed by a **licensed healthcare provider**, who will insist on regular HIV testing and likely offer you risk-reduction counseling, adherence support and routine laboratory tests.

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- Some PrEP users have reported **mild side effects**, including stomach pain, headache and weight loss, especially at the beginning of the regimen. Kidney and bone problems are possible but rare. Talk to your healthcare provider immediately if you are concerned about side-effects.

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- PrEP is **not for everybody**. People interested in PrEP should talk to a knowledgeable healthcare provider to see if it is right for them.

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- You can **start or stop** PrEP at any time but it must be done in consultation with your healthcare provider.
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## Post-Exposure Prophylaxis (PEP)

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PEP is short for post-exposure prophylaxis. It is an HIV prevention strategy that involves taking HIV medications immediately after a single high-risk event, such as condomless sex without the use of PrEP. These medications stop HIV from making copies of itself and spreading throughout your body. PEP must be started as soon as possible to be effective, but no more than 72 hours after you may have been exposed to HIV.

# FAST FACTS:

## ABOUT PEP:

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- Timing is critical when it comes to PEP. The strategy works best when started **as soon as possible** (but no later than 72 hours after exposure) and **continued for 28 days**.
  - PEP is recommended if there was a significant **risk of exposure**. Cases are considered on an individual basis, but examples include condom breakage and sexual assault. People who use PEP must take the medication exactly as **prescribed** by their healthcare provider.
  - **Side effects**, often stronger with PEP, can include diarrhea, headaches, nausea and vomiting.
  - At the end of the 28 days, you are required to **follow-up** with your healthcare provider to make sure that the **treatment worked**.
  - **PEP is safe**. However, it does not guarantee that someone exposed to the virus will not become HIV-positive. Instead, it reduces the chance of that happening.
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## HOW DO I PAY FOR PEP AND PREP?

PEP and PrEP are covered by many private health insurance plans and state Medicaid programs. In some areas, there are programs that can help you access PEP and PrEP even if you are uninsured or are undocumented. Also keep in mind that PEP services are sometimes free to survivors of sexual assault and rape. Ask your HIV test counselor or healthcare provider for options and resources in your area.



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## Dating Undetectable

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One of the most effective ways to prevent the spread of HIV is to date people living with HIV who consistently take their medication and have subsequently lowered the amount of HIV in their bodies to undetectable levels. Prevention options exist for those in relationships where one partner is not yet undetectable.

**While undetectable, a person living with HIV remains in good health, and it is virtually impossible for them to pass the virus onto someone else.**



# Know Your Facts — Debunk the Myths

## MYTH:

**“I am on PrEP.  
I don’t need to  
use condoms.”**

## FACT:

When taken as prescribed by a knowledgeable healthcare provider, PrEP provides a very high level of protection against HIV. However, PrEP does not protect against other STIs or unwanted pregnancy. Using a condom can provide additional protection.

## MYTH:

**“PrEP is only for  
people who have  
a lot of sex and  
don’t want to  
use condoms.”**

## FACT:

There are many reasons why people might want to take advantage of PrEP. Perhaps they are in a relationship with a person living with HIV. Perhaps they have trouble consistently using condoms. Whatever the reason, PrEP is a safe and highly effective HIV-prevention strategy that should be seen as a welcome addition to the HIV prevention toolbox.

# Takeaway Points

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**Sex** should be a pleasurable and

**STRESS-FREE**

experience.

**Promote sexual health** by choosing the **HIV-prevention strategy**, or combination of strategies, that works best for you and your sexual partners.



**Use condoms** and other latex barriers consistently and correctly.



Take **HIV medications** as prescribed.



If you are **HIV-positive**, stay

**UNDETECT-ABLE**

by consistently taking your medications.

If you are **HIV-negative**, think about using HIV medications such as



as a form of **additional protection** against HIV.



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# Glossary

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**AIDS (Acquired Immune Deficiency Syndrome):**

the stage of HIV where the immune system is severely compromised and some illnesses may cause major problems

**Condom:**

a flexible sheath, usually made of thin rubber or latex, designed to cover the penis or vagina during sexual intercourse to prevent pregnancy or sexually transmitted infections

**Condomless Sex:**

a term used to describe sex without condoms or sex without the use of HIV medications prior to a sexual encounter (i.e., PrEP)

**HIV (Human Immunodeficiency Virus):**

a virus that attacks the body's immune system, which is crucial to fighting off infections and diseases

**Opportunistic Infection:**

a term used to describe an illness that usually does not cause disease in someone with a healthy immune system

**Pre-Exposure Prophylaxis (PrEP):**

an HIV prevention strategy that currently involves taking a once-daily pill to reduce the likelihood of acquiring HIV

**Post-Exposure Prophylaxis (PEP):**

an HIV prevention strategy that involves taking HIV medications immediately after a single high-risk event, such as condomless sex without the use of PrEP

**Sexually Transmitted Infection (STI):**

an infection that can be passed on through oral, anal or vaginal sex via bodily fluids or, in some cases, skin-to-skin genital contact

**Transmission:**

the action or process by which something (e.g., virus) is passed on

**Undetectable:**

a term used to describe what happens when the amount of HIV in a person's body cannot be detected by standard HIV tests (i.e., undetectable viral load)

**Viral Load:**

the amount of HIV in the body

**Window Period:**

the length of time it takes for an HIV test to detect whether an infection has occurred

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# HRC Resources

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HRC provides many free resources on LGBTQ health generally and HIV specifically. Visit [www.hrc.org/hiv](http://www.hrc.org/hiv) to find:

How HIV Impacts LGBTQ People

Frequently Asked Questions About HIV

Debunking Common Myths About HIV

Pre-Exposure Prophylaxis 101

How Do I Talk to My Provider About PrEP?

Safer Sex

Safer Sex for Trans Bodies

Transgender People & HIV: What We Know

Healthcare Equality Index

HIV & AIDS and Employment Discrimination

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# Additional Resources

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## **HIV Testing Site and Care Locator**

[locator.aids.gov](http://locator.aids.gov)  
[gettested.cdc.gov](http://gettested.cdc.gov)  
[www.freehivtest.net](http://www.freehivtest.net)

## **LGBT-friendly Provider Directory**

[www.glma.org](http://www.glma.org)

## **State HIV & AIDS Hotlines**

[hab.hrsa.gov/gethelp/statehotlines.html](http://hab.hrsa.gov/gethelp/statehotlines.html)

## **PrEP**

[www.greaterthan.org/get-prep/](http://www.greaterthan.org/get-prep/)  
[www.prepwatch.org](http://www.prepwatch.org)  
[www.prepfacts.org](http://www.prepfacts.org)  
[www.nmac.org/prepareforlife](http://www.nmac.org/prepareforlife)

## **PEP**

[www.avert.org/post-exposure-prophylaxis-pep.htm](http://www.avert.org/post-exposure-prophylaxis-pep.htm)  
[www.who.int/hiv/topics/prophylaxis/en](http://www.who.int/hiv/topics/prophylaxis/en)

## **Local Health Department**

[www.naccho.org/about/lhd/](http://www.naccho.org/about/lhd/)

## **HIV Stigma/Criminalization**

[www.seroproject.com](http://www.seroproject.com)  
[www.lambdalegal.org](http://www.lambdalegal.org)  
[www.hivlawandpolicy.org](http://www.hivlawandpolicy.org)

## **Syringe Exchange**

[www.nasen.org/programs](http://www.nasen.org/programs)

## **Insurance**

[www.healthcare.gov](http://www.healthcare.gov)

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# References

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The information contained in this guide is current as of February 2017 . Be sure to check out the references below for changes or updates to the content.

**AIDS.gov — Access to U.S. Government**

**HIV/AIDS Information**

[www.aids.gov](http://www.aids.gov)

**AIDS Info — Offering Information on HIV/AIDS**

**Treatment, Prevention and Research**

[aidsinfo.nih.gov](http://aidsinfo.nih.gov)

**AVERT — Averting HIV and AIDS**

[www.avert.org](http://www.avert.org)

**Centers for Disease Control and Prevention — HIV/AIDS**

[www.cdc.gov/hiv](http://www.cdc.gov/hiv)

**Health Resources and Services Administration**

**— HIV/AIDS Programs**

[hab.hrsa.gov](http://hab.hrsa.gov)

**NAM AIDSmap: HIV & AIDS**

**— sharing knowledge, changing lives**

[www.aidsmap.com](http://www.aidsmap.com)

**New York City Department of Health and Mental Hygiene**

**— New Ways to Prevent HIV**

[www.nyc.gov/html/doh/html/living/pep-pep.shtml](http://www.nyc.gov/html/doh/html/living/pep-pep.shtml)



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# Acknowledgements

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## **GMHC**

446 West 33rd St., New York, NY 10001  
[www.gmhc.org](http://www.gmhc.org)

## **NAESM**

2140 Martin Luther King, Jr. Dr., NW, Atlanta, GA 30310  
[www.naesm.org](http://www.naesm.org)

## **NASTAD – National Alliance of State & Territorial AIDS Directors**

444 North Capitol St., NW, Suite 339, Washington, DC 20001  
[www.nastad.org](http://www.nastad.org)

## **NMAC**

1931 13th St., NW, Washington, DC 20009  
[www.nmac.org](http://www.nmac.org)

## **The Red Door Foundation, Inc.**

1750 Madison Ave., Suite 600, Memphis, TN 38104  
[www.trdfmemphis.com](http://www.trdfmemphis.com)

## **Whitman-Walker Health**

1701 14th St., NW, Washington, DC 20009  
[www.whitman-walker.org](http://www.whitman-walker.org)

## **Young Black Gay Men's Leadership Initiative**

[www.ybgli.org](http://www.ybgli.org)

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## **HUMAN RIGHTS CAMPAIGN FOUNDATION**

The Human Rights Campaign Foundation improves the lives of lesbian, gay, bisexual, transgender and queer (LGBTQ) people by working to increase understanding and encourage the adoption of LGBTQ-inclusive policies and practices. We build support for LGBTQ people among families and friends, co-workers and employers, pastors and parishioners, doctors and teachers, neighbors and the general public. Through various programs and projects, we are enhancing the lived experiences of LGBTQ people and their families as we change hearts and minds across America and around the globe.

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## **AIDS UNITED**

AIDS United's mission is to end the AIDS epidemic in the United States. We seek to fulfill our mission through strategic grantmaking, capacity building, policy/advocacy, technical assistance and formative research.

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For more copies of this guide, additional HIV prevention and treatment resources, or more information about the Human Rights Campaign, please contact us at [www.hrc.org](http://www.hrc.org) or 1640 Rhode Island Ave, N.W., Washington, D.C., 20036.





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