

# Wellness Guide

WHAT YOU NEED TO KNOW ABOUT  
**HIV PREVENTION AND CARE**



# WELCOME!



Did you know that people with substance use disorders are more vulnerable to acquiring HIV?

But there's good news! Medical advancements can reduce vulnerability to HIV & improve health outcomes for people living with HIV.



This guide has basic information about HIV prevention and treatment for individuals receiving substance use treatment. It's split into individual sections that you can use as best suits your needs.

Continue reading to learn how this information can contribute to your overall wellness planning!

# TABLE OF CONTENTS

<b>Section 1: Understanding HIV</b>	<b>4</b>
About HIV	5
Stages of HIV	6
<b>Section 2: HIV Transmission and Prevention</b>	<b>7</b>
HIV transmission	8
Substance use & HIV Vulnerability	9
Harm Reduction for HIV Prevention	10
Medication for HIV Prevention	11
HIV and Sexually Transmitted Infections	12
Prevent Sexual Transmission	13
HIV Prevention During Pregnancy	14
<b>Section 3: HIV Testing</b>	<b>15</b>
About HIV tests	16
Types of HIV tests	17
Resources for HIV Testing	18
<b>Section 4: HIV Treatment</b>	<b>19</b>
Key Terms	20
Medication for HIV	21
Starting Treatment	22
Blood work	23
Appointment preparation	24
At the Appointment	25
Your Medical Care	26
Resources for HIV Treatment	27
<b>Section 5: Medication Adherence</b>	<b>28</b>
Taking Your Medication	29
Problem Solving	30
Tips & Tricks for Adherence	31
Treatment as Prevention	32
Resources for HIV Treatment	33
<b>Section 6: Appendix</b>	<b>34</b>
Glossary	35
Worksheet: Preparing for a Medical Visit	37
Worksheet: Questions for my Medical Provider: Tests & Evaluations	38
Worksheet: Questions for my Medical Provider: Treatment	39
Worksheet: Keeping Track of Treatment: Oral Medication	40
Worksheet: Keeping Track of Treatment: Injection Medication	41
<b>Section 7: Resources</b>	<b>42</b>
Resources	43

## **Section 1:**

# **Understanding HIV**

# ABOUT HIV

HIV stands for:

**H**uman **I**mmunodeficiency **V**irus

**HIV damages the body's immune system**

Without treatment, HIV increases vulnerability to serious illness and death

**Without treatment, HIV is progressive**

HIV makes it harder for the body to fight off other illnesses

**HIV is Treatable!**

With treatment, people living with HIV can live long, healthy lives

## **How does HIV work?**

- HIV infects immune cells and stops them from protecting the body.
- Untreated, HIV can destroy the immune system over a period of 7 to 9 years and can lead to death.

## **HIV is a manageable, chronic illness that requires ongoing treatment.**

- For many people, treatment means taking one pill a day or an injection every 2 months with few or no side effects.
- People living with HIV can even prevent transmitting HIV to others by taking their medication.

# STAGES of HIV

Thinking about HIV as developing over 3 stages can help understand how HIV progresses overtime if it is not treated.

## Stage 1: Acute or Primary Infection

This is the Initial period after acquiring HIV. Many people get flu-like symptoms – often, folks think that they have the flu.

There is a very high amount of HIV virus in the body, so a person could transmit HIV to someone else, even if they don't know they have HIV.

## Stage 2: Chronic or Asymptomatic Infection

This stage can last a few years, and many people look and feel healthy during this period, *even without medication.*

Even though someone might feel fine, HIV is still damaging the immune system. Without medication, HIV will progress to the third stage.

## Stage 3: Advanced HIV or AIDS


This is a clinical diagnosis that is caused by HIV – it is diagnosed when someone's immune system is very damaged and when they have been diagnosed with certain illnesses.

If untreated, people with HIV are at risk of developing opportunistic infections that can lead to serious illness and death.

With medication, health can improve across all stages, even if someone reaches Stage 3.

However, it is important to start HIV treatment as soon as possible after diagnosis.



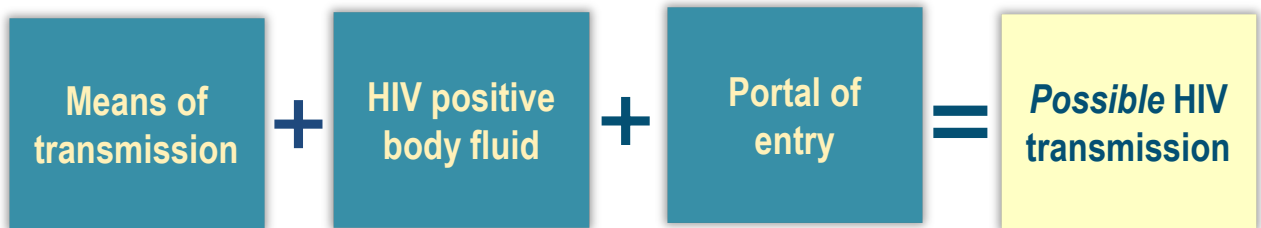


## **Section 2: HIV Transmission and Prevention**

# HIV TRANSMISSION

The only bodily fluids that can transmit HIV are blood, semen, rectal fluids, vaginal secretions, & breast milk.

In order for HIV to be transmitted, there has to be an action that can transmit, an HIV positive body fluid and a way for that body fluid to get inside another person's body. Even if all of those things are true, not every exposure leads to an HIV infection.



Transmission via blood can occur in several ways, including sharing needles or syringes for injecting drugs, steroids, hormones, or silicone. If sex involves tearing or abrasions, blood can be introduced.



An exposure doesn't necessarily lead to a transmission! And, all of the above factors must be true for HIV to be transmitted.



# SUBSTANCE USE & HIV VULNERABILITY

- There are about 1.2 million people living with HIV in the US, including around 154,700 people who don't know their status.<sup>1</sup>
- In Pennsylvania, there are an estimated 40,600 people living with HIV.<sup>2</sup>
- Because people who use substances have increased vulnerability to HIV, it is recommended that they are screened for HIV yearly.<sup>3</sup>

## Why do people with substance use disorder have increased vulnerability to acquiring HIV?

Using injection drugs can **lead to HIV transmission** if you share needles, syringes, or other drug preparation equipment. About 1 in 10 new HIV infections are attributed to injection drug use.

Drinking alcohol and ingesting, smoking, or inhaling drugs are also associated with increased risk for HIV.

Alcohol and other drug use can impair judgment and reduce inhibitions.

This can lead to practices, like condomless sex or sharing syringes, that make people more likely to get and transmit HIV



1 <https://www.cdc.gov/hiv/basics/statistics.html>;

2 <https://www.health.pa.gov/topics/Documents/Programs/HIV/2021%20Annual%20HIV%20Surveillance%20Report.pdf>

3 <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2020-updated-vol-33.pdf>

# HARM REDUCTION FOR HIV PREVENTION

Using sterile needles or syringes and injection equipment can greatly reduce your risk of acquiring HIV. Getting new syringes ensures that they are sterile.

If getting new needles or syringes isn't an option for you, then there are ways you can sterilize the syringes that you have.



It is best to use sterile needles or syringes AND works every time!

## STERILIZATION TIPS

- If new, sterile needles or syringes aren't available, cleaning should follow 3 steps:
  1. Rinse needle or syringe out with clean water. *(repeat until water is clear)*
  2. Disinfect needle or syringe with pure bleach.
  3. Rinse needle or syringe out again with clean water.
- Only sterile needles or syringes should ever draw mixing water

## WHERE TO GET STERILE SYRINGES OR NEEDLES

- Local syringe service programs (SSPs)
  - SSPs provide sterile syringes and injection equipment.
  - Find an SSP here: <https://nasen.org/>
- Pharmacies *(some sell new needles or syringes)*
- Doctors *(some can write prescriptions for new needles or syringes)*

Even needles or syringes that haven't been used for a while should be sterilized – viruses can still be infectious!



<https://harmreduction.org/resource-center/harm-reduction-near-you/>

The National Harm Reduction Coalition has links that can help you find harm reduction resources and tools that you need to keep yourself and your community safe & healthy.

# MEDICATION FOR HIV PREVENTION

PrEP is medication that can prevent HIV transmission from sex or injection drug use.

## PREVENT HIV WITH PrEP (*Pre Exposure Prophylaxis*)

PrEP is medication that people can take to prevent HIV  
PrEP is for **ANYONE** looking to prevent HIV

- PrEP is recommended for sexually active people who don't know the HIV status of their sexual partners or whose partners are living with HIV, and for people who use injection drugs
- PrEP can be taken as a pill once per day or as an injection every 60 days.



What should I know about PrEP?

- PrEP is only effective in people who *do not* have HIV.
- *The more consistently PrEP is taken, the more effective it is!*
- PrEP does not prevent other sexually transmitted infections or pregnancy.
- When using PrEP, continue to use prevention tools like condoms & sterile injection equipment.

## PREVENT HIV AFTER AN EXPOSURE WITH PEP (*Post Exposure Prophylaxis*)

- PEP is medication that can prevent HIV transmission after an exposure.
- If you may have been exposed to HIV, ask about PEP right away.
- **PEP is for emergency situations and must be started within 72 hours of exposure.**



See our PrEP Patient Guide for more detail! ➡



# HIV AND SEXUALLY TRANSMITTED INFECTIONS

Sexually transmitted infections (STIs) like chlamydia, gonorrhea, and syphilis **increase a person's vulnerability** to both **transmitting** and **acquiring HIV**. Both a history of and current STIs increase HIV vulnerability.



## How do STIs increase HIV vulnerability?

- STIs often cause sores or breaks in the skin that increase the chance of transmitting or acquiring HIV through blood.
- STIs also affect cells in such a way that makes them more susceptible to HIV infection, meaning that the chance of HIV infection after exposure is increased.

## What behaviors increase vulnerability to both HIV & STIs?

- Anal, vaginal, or oral sex without a condom.
- Sex partners with unknown HIV and STI statuses.
- Alcohol and other drug use lowers inhibitions and can lead to sex without a condom and/or with others of unknown HIV or STI status.

## Get Tested and Treated for STIs!

If you are sexually active, it is important to be regularly tested for STIs. Regular testing allows you to receive STI treatment, which reduces both risk of transmitting STIs to sexual partners and vulnerability to HIV acquisition. Encourage your sexual partners to also get tested and share their STI status with you.

Visit [gettested.cdc.gov](https://www.gettested.cdc.gov)  
for more STI info and testing sites near you



# PREVENT SEXUAL TRANSMISSION

Although use of PrEP can prevent transmission of HIV, condom use is always recommended to reduce the risk of transmission even more and to prevent sexually transmitted infections (STI).

When used the right way every time, condoms – both internal (female) and external (male) – are **highly effective in preventing HIV and STIs**



## *Tips for proper condom use:*

- Use a new condom for every time you have penetrative sex.
- Don't double up! This can increase likelihood of condom breakage.
- Make sure you use enough lubrication to avoid tearing the skin and reduce risk of HIV transmission.



- *Avoid oil-based lubricants, like baby oil, lotion, Vaseline, or cooking oil as they will cause latex condoms to break.*

While male-to-male sexual contact accounts for the greatest portion of new HIV cases, the next highest group is among women through heterosexual contact.<sup>3</sup>



**Sexual wellness and harm reduction is important for everyone!**

# HIV PREVENTION DURING PREGNANCY



HIV can be transmitted to the baby during pregnancy, childbirth and breastfeeding. This is referred to as “perinatal transmission.”

**All pregnant people should be tested twice during every pregnancy;** as early as possible and again in the third trimester.



**People who are pregnant or are considering getting pregnant can prevent HIV with PrEP.**



Since PrEP can prevent HIV, PrEP is a great option to consider for folks who have a partner living with HIV or who are vulnerable to HIV transmission.

If a pregnant person is HIV positive, it is important to take HIV medications as prescribed to greatly reduce risk of transmitting HIV to the baby.

People who are HIV positive who want to breastfeed should talk with their doctors to understand their options. HIV medication can greatly reduce, but not eliminate, the risk of HIV transmission through breastmilk.



**Section 3:**

# **HIV Testing**

# ABOUT HIV TESTS

HIV testing should happen yearly for people with substance use disorders



## When you get tested for HIV, you can also:

- ✓ Get tested for sexually transmitted infections.
- ✓ Be connected to care immediately if your test indicates that you have HIV.
- ✓ Explore ways you can continue to prevent HIV infection if your test indicates that you do not have HIV.

## Different types of HIV tests have different *Window Periods*

What's a Window Period?



The time period between HIV infection and a test's ability to detect an HIV infection

An incident like sharing injection equipment or having condomless sex with someone living with HIV



What's an Exposure to HIV?



How to select a test?



If you haven't had a possible exposure during the test window period, and your result is negative for HIV, you can be confident you don't have HIV. If you've had an exposure during the test window period, get retested!



# TYPES OF HIV TESTS

There are different types of HIV tests, and they look for different things. Some look for antibodies, proteins made by the body's immune system when it encounters a virus, and others look for the virus itself.

## Rapid Tests

- Use a fingerstick or oral fluid
- Results within 20 minutes
- Window period is up to 90 days.
- Can be done at home or in a clinical setting

## Lab-Based Tests

- Require a blood draw that is sent to a lab for analysis.
- Most accurate and have the shortest window period (10-45 days)
- Detect the actual virus in the blood
- Needed to confirm Rapid Test results



Some people may have difficulty accessing HIV tests or feel uncomfortable going into a clinic. Self-tests are a good alternative, and you can get them online or at a pharmacy. However, if you have had an exposure within the past 90 days, a home test should not be used.

## HIV Self-Tests

**Rapid Self-Tests** use oral fluid and results are available in 20 minutes, they are accurate in detecting HIV, but have the longest window period (90 days).

Order a rapid self-test in Philadelphia County at [phillykeeponloving.com](http://phillykeeponloving.com)  
and for the rest of PA at [getmyhivtest.com](http://getmyhivtest.com)

**Mail-In Self-Tests** include supplies to collect dried blood from a fingerstick at home. The sample is then sent to a lab for testing and the results are provided by a health care provider.

Order a mail-in test at [testing.com/tests/at-home-HIV-test/](http://testing.com/tests/at-home-HIV-test/)

# RESOURCES FOR HIV TESTING

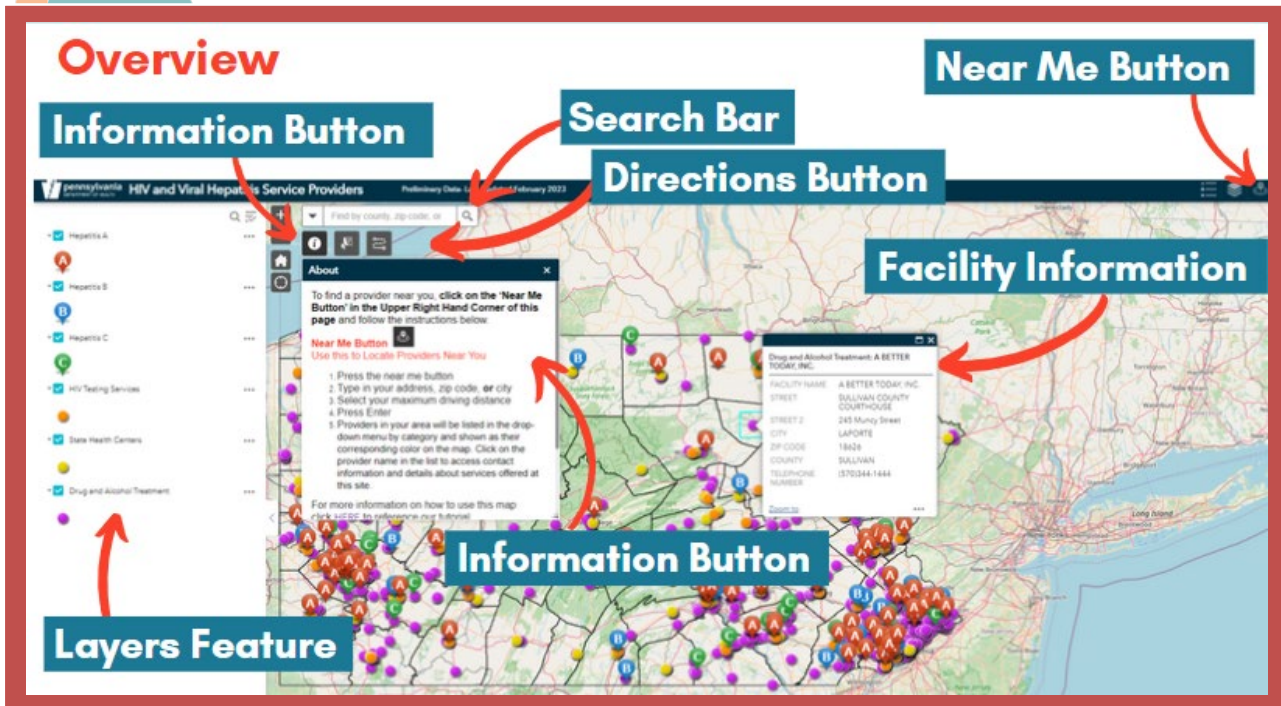
There are many places in PA that offer HIV testing. Visit the link below or scan the QR code to find testing near you.



[bit.ly/DOHmap](https://bit.ly/DOHmap)



Below is a brief overview of how to use the online map of HIV resources.



The screenshot shows the 'HIV and Viral Hepatitis Service Providers' map interface. Key features are labeled with blue boxes and red arrows:

- Overview**: The main title of the page.
- Information Button**: Located in the top right corner of the map area.
- Search Bar**: A search input field at the top of the map.
- Directions Button**: A button to get directions to a selected provider.
- Near Me Button**: A button to find providers near the user's location.
- Facility Information**: A pop-up window showing details for a selected provider, such as 'A BETTER TODAY, INC.' in Sullivan County Courthouse.
- Layers Feature**: A sidebar on the left with a list of categories like Hepatitis A, HIV Testing Services, and Drug and Alcohol Treatment, each with a corresponding colored dot.

The map can be viewed on a computer or mobile device. If you don't have access to either, don't hesitate to ask your medical provider for help!

for more info email: [PAhealthresources@healthfederation.org](mailto:PAhealthresources@healthfederation.org)



**Section 4:**

# **HIV Treatment**

# KEY TERMS

This section will include a lot of terms that might be new to you! Here is a summary of some key terms that will help you understand HIV treatment:

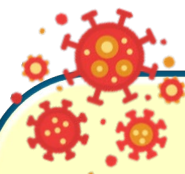


## CD4 Cell

A type of white blood cell that **protects the body from infections**. HIV lowers the number of CD4 cells, making it harder for your body to fight infections.

## CD4 Count

The number of CD4 cells in your blood and a measure of **how well your immune system is functioning**. A normal range is between 500-1500 cells/mm<sup>3</sup> and below 200 is considered life threatening.



## Viral Load

A measure of **how much virus is in the blood**, measured by an RNA/PCR test. On lab work, it will be reported as the number of HIV copies in a milliliter (copies/mL) of blood. **A high viral load means there is more HIV in the body**. Untreated, early HIV infections can have HIV viral loads over 100,000. Viral loads under 200 are considered suppressed.

## Viral Suppression

When the viral load is below 200 copies/ml. **People usually achieve viral suppression 1-6 months after starting treatment**.

Viral Suppression is also known as **undetectable** as the viral load is so low, it **cannot be detected** with traditional viral load tests.



# MEDICATION FOR HIV

HIV medication, **Antiretroviral Therapy (ART)**, is medication used to treat HIV.

HIV damages the immune system by using CD4 cells to replicate. That is, *HIV prevents CD4 cells from doing their job, helping the immune system protect the body*, and instead uses them to make more HIV.

## *How does ART work?*

**ART** works by **stopping the replication of HIV**, which results in less HIV in your system and can allow **the immune system to recover**.

ART is not a cure – it is a **lifelong treatment** that must be taken continually to prevent HIV from replicating and **to improve health**.

- **When you first start ART, pills are recommended.**
  - For many people, this can be one pill per day.
  - Viral load suppression can be achieved in 1-6 months after starting ART.
- Once you achieve an undetectable viral load or viral suppression for at least 3 months, you may consider injectable ART.
  - HIV treatment shots are given by your health care provider once a month when starting injections, and then shift to once every other month.



# STARTING TREATMENT

When you start treatment, your health care provider will ask questions about your health and conduct routine medical exams to determine how HIV is affecting your body, including:



- ✓ Taking a blood sample (*more detail about this on page 23*)
- ✓ Asking about your health history
- ✓ Check for other kinds of health problems that need attention
- ✓ Determine and discuss your treatment plan, including ways to help you follow it
- ✓ Answer your questions!

## **It is very important that you start HIV treatment as soon as possible!**

*Delaying treatment means that HIV will continue to damage your immune system, leaving you vulnerable to illness and increasing risk of transmitting HIV to others.*

Unlike previous types of HIV medication that had severe side effects, **ART is very well tolerated by most people.** Some common short-term side effects, like nausea, fatigue, and trouble sleeping, typically go away after a few weeks. For people taking injectable HIV medication, injection site irritation may occur.

**Are there side effects?**



# BLOOD WORK

Pretreatment blood work helps a medical provider decide what type of treatment is best. Blood work will also be done throughout treatment to learn more about overall health and the impact of HIV on the body. People should expect to get blood work a few times a year.

These blood tests will be used to monitor how HIV is responding to medication. These include lab tests to measure your **CD4 count**, **viral load**, and **drug resistance**.<sup>4</sup>

CD4 Count	Viral Load	Resistance
<ul style="list-style-type: none"><li>• A <b>CD4 Count</b> is a measure of how well a person's immune system is functioning. Higher CD4 counts indicate better immune functioning.</li><li>• <b>CD4 count</b> will be checked every 3 to 6 months.</li></ul>	<ul style="list-style-type: none"><li>• <b>Viral Load</b> is the amount of HIV in the blood. Lower viral loads indicate better immune functioning.</li><li>• <b>Viral load tests</b> are conducted between 2 and 8 weeks after starting a new HIV medicine and then regularly every 4 to 6 months.</li></ul>	<ul style="list-style-type: none"><li>• <b>HIV Resistance</b> means HIV does not respond, or is resistant to, a certain type of HIV medication.</li><li>• <b>Resistance testing</b> is done at the start of treatment and as needed if a viral load test shows that medications aren't working.</li></ul>



## Important Lab Tests

### **CD4 Count**

The number of CD4 cells in your blood

### **Quantitative/RNA/PCR/Viral load**

Measures how much virus is in the blood

### **Genotypic/Phenotypic/Resistance Tests**

Show whether HIV is resistant to different HIV medications

# APPOINTMENT PREPARATION

*Here are some things to consider as you get ready for your appointment.*



## **Transportation**

If you can't drive, get a ride, or take public transportation to your appointment, there may be resources available to help. Talk to your counselor or ask the front desk at the medical providers office if they have or know about resources.



211 is a resource that can help - Text your zip code to 898-211 or dial 211 to get help from a resource navigator

## **Is there someone you can take with you?**

Many find that having a support person with them can reduce anxiety.

## **Consider writing notes**

It's hard to keep track of a lot of new information – especially when it's complicated medical info! Taking notes will help you keep track of details about your health and medical care.

## **There are no bad questions!**

Medical and health information can sometimes be difficult to understand. Don't be afraid to ask the medical provider to repeat or explain something. It's your health and your medical care, and you deserve to understand what's going on!

## **Patient portals**

Many medical providers have patient portals, which are websites that allow patients to see their personal health information, such as lab results. If this technology isn't familiar to you, ask if there is assistance to learn about using the portal. If you don't have reliable computer, smart phone or internet access, talk to the medical provider about the best way to communicate.



# AT THE APPOINTMENT

## Medical History

Most medical providers will want some information about your medical history. This will help make sure that the medical care they provide – including your HIV treatment – will be the best and safest option for your body. It can be hard to remember some of these details, so take a moment to write them down beforehand!

- Current medications
- Other medical conditions or diagnoses (*diabetes, asthma*)
- If you've been treated for HIV before
- Allergies
- Any documentation or medical records you have
- Insurance information (*if you are uninsured; see page 27 for more information on insurance access*)
- Contact information for other medical providers
- Family history of medical conditions

## The Visit (*tips for both in-person and telehealth visits*)

If possible, it can be helpful to show up or sign in **a few minutes early** to your appointment. This can give you some time to complete any paperwork provided by the front desk and to trouble shoot any problems you may have finding the place or signing in.

Find out what the policies are for rescheduling or missing appointments.

If you care for young children and cannot find childcare, ask the medical provider's office if they allow children to accompany caretakers to medical appointments.



# YOUR MEDICAL CARE

## Tests & Evaluation

It can be helpful to have some understanding of what is happening with your HIV and overall health. While you don't need to memorize or understand every detail, here are some questions you may want to ask.

- What is my CD4 count?

*More on how to understand CD4 count on pages 20 & 23*

- What is my viral load?

*More on how to understand CD4 count on pages 20 & 23*

## Treatment

Starting a new medical treatment can be overwhelming! Here are some questions that might help you understand what to expect from treatment.

- What are my treatment options?
- Side effects
  - What are common side effects?
  - What can I do to manage side effects? (*Over the counter medicine, eating before taking meds, etc.*)
- Are there any drug/drug interactions I should know about?
- What happens if I miss a dose?
- How often will I need to see the medical provider or get blood work done?
- Is there a particular pharmacy that I need to use?



# RESOURCES FOR HIV TREATMENT

Both commercial/private medical insurance and state Medicaid/Medicare will cover medical visits, labs and prescriptions for HIV treatment.

If you need help accessing care, check out the resources below.



PA 211 is a wealth of resources for housing, utilities, food, employment and expenses, health, and mental health.

To get help from a resource navigator, text your zip code to 898-211 or dial 211

## The Ryan White HIV/AIDS Program

Works to provide HIV-related services. Ryan White fills gaps in health care coverage. Find out more at <https://ryanwhite.hrsa.gov>  
Find a Ryan White clinic near you by using the HIV Testing and Care Services locator: <https://locator.hiv.gov/map>

*Many care providers have Ryan White funding, which means that medical case management and other supportive services are available to support you!*

## The Health Center Program

Provides HIV testing and treatment, regardless of ability to pay. Some health centers provide services onsite, and some refer to HIV specialists in the community.  
Find a health center near you by using the HIV Testing and Care Services locator: <https://locator.hiv.gov/map>

## Marketplace

Open Enrollment Nov. 1 through Dec. 15, unless qualify for Special Enrollment Period (SEP).  
More details online. [www.healthcare.gov](http://www.healthcare.gov) 800-318-2596

## Special Pharmaceutical Benefits Program (SPBP)

Assists persons with HIV to obtain medication, pay for some laboratory services, and provide premium assistance with selected Medicare Part C and D plans.  
<https://www.health.pa.gov/topics/programs/HIV/Pages/Special-Pharmaceutical-Benefits.aspx>

## PA Health & Dental Marketplace

Link to additional financial assistance from the American Rescue Plan to lower your monthly payment and/or out-of-pocket expenses. <https://pennie.com/>

## State and local Health Insurance Info & Counseling

Can search by county, zip & city. Population specific resources (aging, vets, etc.) included.  
<https://www.pa211.org/get-help/health/state-local-health-insurance-information-counseling/>

## Navigator Programs

<https://www.pa211.org/get-help/health/navigator-programs/>

## **Section 5:**

# **Medication Adherence**

# TAKING YOUR MEDICATION

## What is “Adherence” and why is it important?

- ✓ Adherence means **to stick to something**.
- ✓ For meds to work, there needs to be **enough medication** in the body for a **long enough time** for it **to STOP HIV FROM REPLICATING**.
- ✓ When someone is non-adherent to their HIV medication, that means they don't take it the way their doctor instructed, it can lead to **DRUG RESISTANCE**.

## What should I know about Drug Resistance?

- If you develop drug resistance to HIV medication, that means certain types of medication will no longer work to treat your HIV, even if they worked in the past.
- When drug resistance develops, people must change to a different type of medication to treat their HIV.
  - *There are other types of treatment options, even if you develop resistance to one type of medicine!*
- Staying adherent to your HIV medication greatly reduces the risk of developing drug resistance.
  - *Sometimes, drug resistance can develop even when people are adherent, so regular labs are very important to monitor your treatment*



**Taking your medication exactly as prescribed and attending ongoing appointments for blood work monitoring keeps you healthy and helps make sure you are taking the best medications.**

# PROBLEM SOLVING

## Setting yourself up for success!

It can be helpful to do some problem solving *before* issues with adherence come up. Some questions to ask yourself:

- What are my concerns about adherence?
- What might make adherence hard for me?
- Who can I talk to about my concerns?
- Where can I get more information?
- Who can help me find solutions to challenges I face?

*What might  
make  
adherence  
difficult?*

- Work, childcare, being busy
- Being tired of taking meds
- Side effects
- Worry about disclosing your diagnosis to others
- Unstable housing
- Mental health challenges
- Arrest or incarceration

**Feeling better can also make adherence difficult!** *You might start to think "maybe I don't need these meds anymore" It's important to remember that taking your meds is what is allowing you to feel better – you DO need these meds!*

*Medical case managers can help with these concerns and connect you to resources in your community*

# TIPS & TRICKS FOR ADHERENCE

## Tools for remembering your meds

- Alarm clock
- Alerts, reminders or alarms in your phone
- Take meds at the same time as something you do every day – *when you brush your teeth, get ready for bed, make coffee*
- Have a friend help remind you
- Keep a pill card in your pocket to keep track of each pill taken
- Put a calendar up and mark each day you take your meds
- Pill boxes
  - Tip! Some pillboxes can be attached to a lanyard so you can keep your meds close to you if you're nervous about theft or sharing your private health information.*

***What tools can YOU think of that might help you keep on track with taking your medication?***

---

---

---



If you miss a dose - Don't beat yourself up! We all forget to do things sometimes.

Don't double up – take the next dose as usual, unless otherwise directed by your doctor.

If you have missed several doses in a row, it's a good idea to check in with your medical provider.

# TREATMENT as PREVENTION

## **Viral Suppression and Treatment as Prevention:**

- When taken as prescribed, ART allows the immune system to recover by lowering the viral load to undetectable levels.
  - *That means that the amount of HIV in the blood gets so low it cannot be detected by standard or traditional viral load tests.*
- When the viral load is undetectable, viral suppression is achieved.
  - *Most people can reach viral suppression within 6 months.*
- Viral suppression of HIV means a normal, healthy life for most people. Additionally, you cannot transmit HIV sexually when you are virally suppressed!



***People living with HIV with a sustained undetectable viral load do not transmit the virus to sexual partners***



## **A viral load that is**

## **Undetectable is Untransmittable**

Staying in HIV treatment helps you get healthy, and it also helps you protect others. You can no longer sexually transmit HIV to others if you have sustained viral suppression (virally suppressed for at least six months) and your viral load is undetectable.



# RESOURCES FOR HIV TREATMENT



There are many places in PA that offer HIV treatment. Visit the link below or scan the QR code to find treatment near you.

[bit.ly/DOHmap](https://bit.ly/DOHmap)

Below is a brief overview of how to use the online map of HIV resources.



A screenshot of the Pennsylvania Department of Health's HIV and Viral Hepatitis Service Providers map. The map shows various colored markers representing different services. Several callout boxes with red arrows point to specific features: 'Overview' points to the top left; 'Information Button' points to the top left and bottom center; 'Search Bar' points to the top search input; 'Directions Button' points to the top right; 'Near Me Button' points to the top right; 'Facility Information' points to a pop-up window for 'A BETTER TODAY, INC.'; and 'Layers Feature' points to the left sidebar menu.



The map can be viewed on a computer or mobile device. If you don't have access to either, don't hesitate to ask your medical provider for help!

for more info email: [PAhealthresources@healthfederation.org](mailto:PAhealthresources@healthfederation.org)

**Section 6:**

**Appendix**

# GLOSSARY

**Acute Infection:** a *new* infection.

**Antibodies:** Proteins made by the immune system when it encounters a virus. Antibodies defend the body against the virus. Some HIV tests look for HIV antibodies.

**Antiretroviral treatment (ART):** HIV medication that stops HIV from replicating and allows the immune system to recover by lowering viral load.

**CD4 cell:** A type of white blood cell that protects the body from infections. HIV lowers the number of CD4 cells, making it harder for your body to fight infections.

**CD4 count:** A measure of how well a person's immune system is functioning. A healthy CD4 count is between 500 and 1500 cubic millimeters.

**Confirmatory Test:** A lab-based HIV test that occurs after an initial HIV test comes back reactive. A confirmatory test confirms an HIV infection.

**Drug Resistance:** Drug resistance is when an HIV medicine is no longer effective for an individual. When this occurs other HIV medicine needs to be used instead.

**HIV:** Human Immunodeficiency Virus.

**HIV Exposure:** An incident like sharing injection equipment or having condomless sex with someone living with HIV.

**HIV PCR (*polymerase chain reaction*) test:** Measures how much HIV is in the blood

**HIV Self-test:** HIV tests that can be done without a medical provider (e.g., at home). In PA, see [getmyhivtest.com](http://getmyhivtest.com) for free home tests. Self-test formats can vary.

**Immunodeficiency:** Refers to a compromised immune system.

**Lab-Based HIV Test:** Require a blood draw that is sent to a lab for analysis. These tests have the shortest window period (10-45 days) and can detect the actual virus in the blood.

**Mail-In HIV Self-Tests:** Include supplies to collect dried blood from a fingerstick at home. The sample is then sent to a lab for testing and the results are provided by a health care provider.

# GLOSSARY

**Opportunistic Infection:** Illnesses caused by various germs that occur more frequently and are more severe among people with immunodeficiency, like people living with HIV, compared to those with healthy immune systems.

**Rapid HIV Test:** uses a fingerstick or oral fluid and provides a result within 20 minutes.

**Rapid HIV Self-Test:** uses oral fluid and results are available in 20 minutes.

**RNA positive:** HIV is present in the blood. This means that someone has an HIV infection.

**RNA negative:** HIV virus is NOT detected in the blood. This means that someone most likely does NOT have an HIV infection.

**RNA test:** A test to look for RNA from HIV in a blood sample. RNA tests can detect HIV in the blood 9-11 days after infection.

**RNA Detected:** HIV RNA is detected in the blood. This means that someone has an HIV infection.

**Reactive:** A preliminary positive test result.

**Resistance testing:** used to determine whether the HIV is resistant or sensitive to certain medications.

**STIs (Sexually Transmitted Infections):** A disease caused by infection with certain bacteria, viruses, or other microorganisms that can be passed from one person to another through blood, semen, vaginal fluids, or other body fluids, during oral, anal, or vaginal sex.

**Undetectable:** the amount of HIV in the blood gets so low it cannot be detected by standard HIV RNA tests.

**Viral Load:** The amount of HIV in the blood and is measured by an RNA/PCR test. When your viral load is high it means there is more HIV in your body.

**Viral Suppression:** When the viral load of HIV is below 200 copies/ml of blood.

**Virus:** an infectious agent that can only replicate inside the cells of a living organism.

**Window Period:** the time period between exposure to HIV and a test's ability to detect an HIV infection.

# Preparing for a Medical Visit

## Patient Worksheet

**NAME:** \_\_\_\_\_

**DATE OF BIRTH:** \_\_\_\_\_

### Current medications:

- 1.
- 2.
- 3.
- 4.
- 5.

### Other medical conditions or diagnoses

*(diabetes, asthma, HCV, etc.)*

### Allergies:

### Family history of medical conditions or diagnoses:

**Have you been treated for HIV before?**    Y        N

If yes, when:

What medicine:

### Checklist of items & information to bring to your first medical appointment:

- Documents such as lab work, medical records
- Insurance information
- Contact information for other medical providers
- List of questions

# Questions for my Medical Provider

## Patient Worksheet: Tests & Evaluation

### Tests & Evaluation

- What is my CD4 count?

*More on how to understand CD4 count on pages 20 & 23*

- What is my viral load?

*More on how to understand CD4 count on pages 20 & 23*

- Do I need resistance testing or other testing in addition to blood work?

# Questions for my Medical Provider

## Patient Worksheet: Treatment

### Treatment

- What are my treatment options?
  
- Side effects
  - What are common side effects?
  
  - What can I do to manage side effects? (*Over the counter medicine, eating before taking meds, etc.*)
  
- Are there any drug/drug interactions I should know about?
  
- What happens if I miss a dose?
  
- How often will I need to see the medical provider or get blood work done?
  
- Is there a particular pharmacy that I need to use?
  
- What kind of follow up or ongoing medical care will I need?
  
- How can I ensure I don't transmit HIV to anyone?





# Keeping Track of Treatment

## Injection Medication: Patient Worksheet

Treatment for HIV is lifelong. This page is meant to help you get started with your treatment and used to your medication schedule.

### Injection Schedule (*for injectable HIV medication*)

How often do I need a new injection: \_\_\_\_\_

Dates for upcoming injection appointments: \_\_\_\_\_

Directions for scheduling new appointments: \_\_\_\_\_

### Questions, Concerns, Notes:

# **Section 7:**

# **Resources**

# RESOURCES

***Sources for more information regarding HIV prevalence, vulnerability, and treatment referenced throughout this patient guide:***

Prevalence of people living with HIV in the US:

<https://www.cdc.gov/hiv/basics/statistics.html>

Prevalence of people living with HIV in Pennsylvania:

<https://www.health.pa.gov/topics/Documents/Programs/HIV/2021%20Annual%20HIV%20Surveillance%20Report.pdf>

Increased vulnerability to HIV among people who use drugs and new HIV cases among women through heterosexual contact:

<https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2020-updated-vol-33.pdf>

HIV Basics regarding understanding care for people living with HIV:

<https://www.cdc.gov/hiv/basics/livingwithhiv/understanding-care.html>

***Useful websites listed throughout this patient guide:***

The **National Harm Reduction Coalition** has links that can help you find harm reduction resources and tools that you need to keep yourself and your community safe & healthy.

<https://harmreduction.org/resource-center/harm-reduction-near-you/>

Find a **Syringe Service Program** here: <https://nasen.org/>

For **STI info and testing sites** near you, go to: [gettested.cdc.gov](http://gettested.cdc.gov)

Find **HIV testing OR HIV treatment** near you: [bit.ly/DOHmap](http://bit.ly/DOHmap)

***Sources for HIV Self-Tests:***

Order a **rapid self-test** in Philadelphia County at

[phillykeeponloving.com](http://phillykeeponloving.com) and for the rest of PA at [getmyhivtest.com](http://getmyhivtest.com)

Order a **mail-in test** at [testing.com/tests/at-home-HIV-test/](http://testing.com/tests/at-home-HIV-test/)

**For resources to help with financial costs associated with HIV treatment, go to slide 27**