

Questions and Answers about HIV/AIDS



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Part I: Questions and Answers for Young People and Students

There are many reasons for a young person to want information about HIV. Maybe you have a school project to complete, or maybe a friend or family member has been affected by HIV. Maybe you realize it's important to know about HIV because you are responsible for your own health and sexual health. Whatever your reason for wanting to know more about HIV, this document is a good starting place.

1. What is the history of HIV/AIDS?

1981 – 1985

In 1981, an unknown illness that affected gay men was reported in hospitals in Los Angeles and New York City. The illness was first called GRID (Gay-Related Immune Deficiency) and many people were dying from it. Soon the name was changed to AIDS (Acquired Immune Deficiency Syndrome). In the very early years, there were a lot of negative feelings (stigma) around AIDS because people were afraid of it. It was a deadly illness and people did not understand how it was passed from person to person. When many people get sick from an illness in the same area at the same time, it is called an epidemic. This was called the AIDS epidemic.

In 1983, HIV (Human Immunodeficiency Virus) was discovered as the virus that causes AIDS. The Centers for Disease Control and Prevention (CDC) found that HIV was only passed, or transmitted, through contact with blood, semen and fluids from the vagina. It was also found that HIV could be passed from mother to child during pregnancy or childbirth or by breastfeeding.

In 1983, the New York State Department of Health began supporting programs to educate people about HIV. Programs that support people affected by HIV/AIDS were also made available. In 1985, the Food and Drug Administration (FDA) approved the first blood test that could tell if a person had HIV. The health department began offering HIV testing.

1986 - 1995

HIV was found in men and women from all walks of life. Many new cases of HIV were happening in people who shared needles to inject drugs. This is because when two people use the same needle, they have contact with each other's blood. By 1990, more than 28,000 people died of AIDS-related causes in New York State. HIV was one of the top causes of death among men under the age of 45. Treatment was not very effective and the medications had many side effects. In the next five years, from 1990

to 1995, more than 74,000 people were diagnosed with AIDS and almost 50,000 people died of HIV related causes in New York State.

1995 - 2014

In late 1995, new drugs became available that changed the path of the epidemic. For the first time, in 1996, the number of people dying from AIDS finally began to decrease. Looking back, that was the real turning point. With new treatments that combined different drugs, fewer people were dying from HIV. Programs that gave sterile needles to people who used drugs brought down the number of new cases among drug users. Another major victory was the use of medications to prevent HIV from being passed from a mother to her infant.

2015 - current

Today, there is still no vaccine or cure for HIV, but treatment is very effective. For many people, treatment for HIV has few or no side effects and is as simple as taking one pill, once a day. HIV is now considered a chronic or long-term illness that can be managed. This means that people living with HIV have healthy, full lives, just like people who are not living with HIV. There is still a lot of work to do to end the AIDS epidemic and remove stigma about HIV. To learn about New York's plan to end the epidemic, see question 8 below. For a complete history of HIV/AIDS, visit: <https://www.aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline/>

2. What is the difference between HIV and AIDS?

HIV (Human Immunodeficiency Virus) is a virus that only affects human beings. A person develops HIV if the virus gets into his or her bloodstream and begins making more and more of itself, or reproducing. People living with HIV may have no symptoms for ten or more years. They may not even know they are living with the virus. An HIV test is the only way to find out if a person is living with HIV.

Once a person is living with HIV, it will attack the body's defense system, known as the immune system. Without treatment, most people living with HIV become unable to fight off germs and other viruses so they can become very sick.

AIDS (Acquired Immune Deficiency Syndrome) is a late stage of HIV disease. According to the CDC, a person living with HIV has AIDS when he or she:

- has a very weakened defense system, or
- develops a serious illness that we know can be caused by HIV.

For a list of these illnesses, visit: www.cdc.gov/mmwr/preview/mmwrhtml/rr5710a2.htm

3. What should I know about HIV prevention and sex?

Adolescence is a time of growth from childhood into adulthood. As you make this change, you may become more interested in sex. You may also have questions about relationships. It is important to find good sources of information. This might be a health care provider, parent, family member, teacher or counselor.

Definition of Sexual Health

Sexual health is having a feeling of wellness related to sexuality. It applies to people of all ages. Sexual health is physical, emotional, mental, and spiritual. It is a central element of human health. Sexual health is based on a positive, equal, and respectful approach to sexuality, relationships and reproduction. Healthy relationships are based on free choice, and are without fear, violence, discrimination, stigma or shame. Sexual health includes: 1) the ability to understand the benefits, risks and responsibilities of sexual behavior; 2) the prevention and cure of disease and other negative experiences and, 3) the possibility of having fulfilling sexual relationships.

A good source of information about sexual health is the *Take Control!* Campaign. *Take Control!* encourages responsible sexual health choices. It offers condoms, HIV and STD (sexually transmitted disease) information and helps build communication skills with partners. The goals of *Take Control!* are to:

- promote positive sexual health to New York's teens and young adults;
- link users to local resources;
- encourage open and honest communication with partners and trusted role models;
- increase awareness and prevention of STDs, HIV and unplanned pregnancy; and
- encourage behaviors that reduce STDs, HIV, and unplanned pregnancy.

Take Control! campaign includes a website made in partnership with the ACT for Youth Center of Excellence at Cornell University found at www.nysyouth.net/sexual_health and a Facebook page, www.facebook.com/takecontrol.

4. What should I know about HIV prevention and substance use?

Making healthy choices about substance use is important for young people. There are many different drugs or substances that a young person might be exposed to at school, through friends or even at home. These can include things like:

- Alcohol
- Marijuana
- Synthetic marijuana (sometimes called K2)
- Prescription opioids like codeine, oxycontin, hydrocodone and others
- Ecstasy
- Attention deficit disorder (ADD and ADHD) drugs
- Cocaine
- Heroin

Misuse of prescription drugs, especially pain killers, or any other substance might start out feeling OK. But it can quickly have negative effects on your health. It can also hurt relationships with friends and family. Use of substances can affect your judgment and lead to sexual behavior that puts you at risk for HIV and other STDs. Too many young people think that taking prescription opioids is safe but it can quickly lead to addiction and injecting drugs. There are some good resources for information about young people and substance use. Check out the resources available at: www.oasas.ny.gov.

5. If I need to write a school report about HIV /AIDS, where can I find information and statistics?

Part Two of this document has a lot of information about HIV. So does the Department of Health website at www.health.ny.gov. You can find medical information, community resources and statistics. The Health Department tracks the number of cases of HIV. It is important to know how many people are living with HIV in different areas. The Health Department tracks the number of cases of HIV by gender, race, ethnicity and age. A person who studies numbers about health conditions is called an epidemiologist. The Department of Health prepares reports on HIV and AIDS that you can use in a school report. You can learn about this at www.etedashboardny.org or see the reports at www.health.ny.gov/diseases/aids/general/statistics/annual/

Check out the Glossary if you are looking for information or specific vocabulary related to HIV/AIDS.

6. What is the New York State Youth Sexual Health Plan?

The New York State Youth Sexual Health Plan is a guide that was created to make sure that all New York State youth have access to correct sexual health information and health services. The Youth Sexual Health Plan was developed by the New York State Department of Health with other state agencies. The plan includes ideas for schools, community leaders, parents, health care providers and others. There are also ideas about how young people can educate each other and help their communities. If you would like to learn more about the plan, check it out at: www.health.ny.gov/community/youth/development/docs/nys_youth_sexual_health_plan.pdf

You can be a leader in your community!

Do you have a passion to help others or do you see something in your community that needs change? Get involved with others and take initiative. You may find that you can meet or exceed your goals.

7. How can I get involved in helping others and being a leader?

The ACT for Youth Network is for young people from all over New York State who want to help make their health and wellness, and that of others in the communities they live in, better. The ACT for Youth Network:

- Creates ways for youth to be heard by decision makers;
- Connects policymakers to young people's ideas and knowledge;
- Supports health and leadership among young people;
- Links youth to one another to share ideas, challenges, and strategies

You can learn more at www.nysyouth.net/.

8. Will we ever see an end to the HIV/ AIDS epidemic?

In 2014, New York State Governor Andrew Cuomo announced a plan to end the AIDS epidemic by the end of 2024. The goal is to lower the number of new HIV cases to fewer than 750 per year. Other goals put in place by New York State are to have no new cases of HIV from injection drug use, and to have no deaths caused by AIDS. The plan calls for better access to HIV testing, HIV treatment and HIV prevention resources. Efforts to end the AIDS epidemic may lead to young people, like you, being part

of the first AIDS Free Generation. You can learn more about the effort to end the AIDS epidemic at www.etedashboardny.org or www.health.ny.gov/ete. You can also learn about the different programs and services that are available to address HIV by visiting About the AIDS Institute.

In the next section you will find more detailed information about HIV transmission, prevention, testing, importance of health care and treatment, and human rights, stigma, and confidentiality. It is a little more explicit and intended for older adolescents or adults.

You've already started doing your part to help end the AIDS epidemic! By reading either part of this document you are getting the right information, which helps to end stigma and promote healthy communication. At the end of this document, you will find a glossary and a list of resources that can help you if you need more information for yourself or a school report. If you have questions, you can talk to a parent, health care provider (doctor or nurse), a teacher, or any trusted adult.

Part II: Questions and Answers About HIV

Transmission

1. How is HIV transmitted?

HIV is spread when blood, semen or vaginal fluids from a person living with HIV who is not virally suppressed gets into the bloodstream of another person. These body fluids are present during sexual activity, which explains why HIV can be passed from one person to another during different sexual behaviors. The risk of transmission depends on the type of sexual behavior. Oral sex, when a person puts his or her mouth on another person's genitals, has a low risk of passing HIV. Vaginal intercourse, when a man puts his penis inside a woman, is a higher risk activity for passing HIV. The sexual behavior with the highest risk is anal intercourse, when a man puts his penis into the anus of another man or woman. If either partner is living with HIV, the virus may be transmitted, especially if blood is present during sex. The risk of transmission for any of these behaviors can be lowered in a variety of ways, including:

- Condom use (see question #5)
- Antiretroviral treatment for the person living with HIV
- Pre-exposure prophylaxis or PrEP, a daily medication that a person who is not living with HIV can take to protect themselves (see question #14).

A person living with HIV who is on HIV treatment and virally suppressed for 6 months or longer has effectively no risk of passing HIV to a partner through sex.

Substance Use Transmission: Sharing needles and works during injection drug use is a high-risk behavior for passing HIV from one person to another. Since blood may be present in the needle, syringe, cooker or water used during injecting, HIV can be easily passed when people share any of these equipment items. By always using sterile injection equipment and not sharing equipment can help protect people who inject drugs from HIV. A special assessment must be conducted for people who inject drugs under 18 years of age who request enrollment in syringe exchange programs. To find syringe exchange programs near you, visit www.thepointny.org. People who inject drugs may also consider taking PrEP, a daily medication that can prevent an HIV negative person from getting HIV. Please see questions 6 & 7 to find out more about how to protect yourself and obtain new injection equipment in New York State.

Mother to Child Transmission: HIV can also be transmitted from mother to child. Please see question #3 for more information.

Blood Transfusion: At the beginning of the AIDS epidemic, some people became a person with an HIV diagnosis from receiving a blood transfusion. With testing of the blood supply since 1985, there is no longer a risk of getting HIV when receiving a transfusion.

2. What are the ways that HIV cannot be transmitted?

HIV is not like the flu or a cold. It is not passed through casual contact or by being near a person who with HIV. It cannot be transmitted through saliva, shaking hands, kissing, mosquito bites, living in the same house as someone living with HIV (including sharing utensils or drinking cups), using restrooms, swimming pools, hot tubs, or drinking fountains.

3. Can a woman living with HIV pass the virus on to her baby?

Yes. A woman who has HIV can pass the virus to her baby during:

- pregnancy
- delivery
- breastfeeding

There are medicines that a woman living with HIV should take during pregnancy, labor, and delivery to protect her health and *greatly reduce* the chance that she will pass the virus to her baby. Medication is also given to the infant right after birth and for the first weeks of life. It is very important for all women to know their HIV status before they become pregnant, or very early in their pregnancy, so that they can take full advantage of these medicines and make informed decisions. A second HIV test is also recommended late in the pregnancy to identify if the woman was exposed to HIV during the pregnancy. Since HIV is also found in breast milk, women living with HIV should not breastfeed their babies.

4. What does Undetectable = Untransmittable (otherwise known as U=U) mean?

U=U means undetectable = untransmittable. U=U was put forth by the Prevention Access Campaign (<https://www.preventionaccess.org/undetectable>). The Prevention Access Campaign is a health equity initiative to end the dual epidemics of HIV and HIV-related stigma by empowering people living with, and vulnerable to HIV, with accurate and meaningful information about their social, sexual, and reproductive health.

In developing U=U, the Prevention Access Campaign reviewed data from several large-scale studies and compiled the findings into a statement which many leading scientists and public health organizations have endorsed.

The U=U Consensus Statement is:

People with HIV on ART with an undetectable viral load in their blood have a negligible risk of sexual transmission of HIV. Depending on the drugs employed it may take as long as six months for the viral load to become undetectable. Continued and reliable HIV suppression requires selection of appropriate agents and excellent adherence to treatment. HIV viral suppression should be monitored to assure both personal health and public health benefits.

When making decisions about HIV prevention, individuals and couples should explore their level of comfort with the full range of prevention options and make decisions regarding use of U=U, condoms or PrEP accordingly.

Prevention

5. What can a person do to avoid getting HIV through sexual behavior?

There is no vaccine to prevent HIV but there are several ways a person can feel confident about avoiding HIV through sexual behavior. Practicing abstinence, that is, not having vaginal or anal intercourse, is one way to protect yourself from HIV. Cuddling, hugging, kissing or mutual masturbation have no risk of passing HIV from one partner to the other. Mutual monogamy, where both partners have been tested and know they are both HIV negative and are not having sex with anyone else, also provides protection.

Here are other choices that some people make to avoid HIV. These approaches offer a very high level of protection:

- If you have a partner who is living with HIV, if he or she is on effective treatment and maintains an undetectable viral load (i.e. the person is virally suppressed), for 6 months and beyond the risk of transmission through sex is negligible.
- Using a condom consistently and correctly every time you have sex is extremely effective in preventing HIV.
- Pre-Exposure Prophylaxis (PrEP): PrEP is a medication for HIV negative individuals to take in order to prevent HIV. PrEP is offered in two forms: a pill or an injection every 2 months. When taken consistently, PrEP has been shown to reduce the risk of HIV by 92-99%.
- Giving and receiving oral sex is considered a low-risk activity for HIV transmission.

If a person has vaginal or anal intercourse without condoms or PrEP, there are important ways to reduce the risk of HIV transmission. These are considered harm reduction strategies, because there is still a risk of getting HIV if a partner is living with the virus and is not virally suppressed.

Use of lubrication: Extra lubrication, like KY jelly, can reduce the chance of cuts and tears in the skin or mucus membranes of the penis, rectum or vagina. This reduces the chance of blood being present and reduces the ability of HIV to enter the body.

- **Strategic Positioning:** During anal sex, there is a penetrative partner (“top”) and a receptive partner (“bottom”). Being the penetrative partner is less of a risk for acquiring HIV than being a receptive partner. However, there is still an element of risk involved in both positions.
- **Frequent STD screening and treatment:** A sore or inflammation from an STD may allow HIV to enter the body of a person who does not have HIV, when it typically would have been stopped by intact skin. For people living with HIV, having an STD/STI can increase the chance of passing the virus to others.

6. How can a person get condoms to prevent HIV?

A person can get condoms in a variety of ways. The following programs provide condoms free of charge.

NYS Condom Access Program: The Department of Health makes free condoms available to eligible organizations which provide them to the public. For information about nearby organizations visit: <http://www.health.ny.gov/diseases/aids/consumers/condoms/nyscondom.htm> or send an e-mail to: nyscondom@health.ny.gov . Call or visit the organization to learn about how to get condoms and how many they provide at a time.

New York City: NYC Condom: Free male condoms, female condoms and lube. For more information, dial 311 or visit <https://www.nyc.gov/site/doh/health/health-topics/condom.page>

Condom Access in Schools: School districts may make condoms available to students as part of their district’s HIV/AIDS instruction program. The New York State Education Department (NYSED) has established a process and an assessment rubric (<http://www.p12.nysed.gov/sss/documents/NYSED-CAP-update.4.25.14.pdf>) for the establishment of a Condom Availability Program(CAP), which should be completed and forwarded to NYSED for review and approval. Following approval, school districts can then request condoms from the NYS Condom program (available at <https://www.health.ny.gov/diseases/aids/consumers/condoms/nyscondom.htm>).

Condoms are also being distributed through the **Statewide Hotline (800-541-2437)** or the **HIV Counseling Hotline (800-872-2777)**. Currently, their policy is to restrict the orders to 10 condoms per call; ages 18 years and above; only New York State addresses.

Medicaid will also cover the cost of condoms. Providers can write a prescription for them, but you will need to ask your medical provider to do so. You can also buy condoms at grocery stores, drugstores and online.

7. What can a person do to avoid HIV through drug use?

People who use drugs should always use new needles, syringes, and works and avoid sharing them. If getting new equipment is not a possibility, people who inject drugs can lower the risk of HIV transmission by cleaning needles and works with bleach immediately after use and just before reuse.

Directions for cleaning your syringes:

Step 1: Rinse the syringe with sterile water.

Step 2: Rinse the syringe with bleach.

Step 3: Rinse again with new sterile water.

New York State has many ways to get new, clean syringes, please see question #7.

8. How can a person who injects drugs or other substances obtain sterile injection equipment?

People who inject drugs are encouraged to seek out Syringe Exchange Programs (SEPs) to receive free sterile syringes to prevent HIV among themselves and their peers.

Three ways to get new, sterile syringes in New York State are:

1. At a Syringe Exchange Program, also called needle exchange programs: At SEPs, located in some areas of New York State, people who use drugs can exchange used syringes for new, sterile syringes. To find SEPs, call the New York State HIV/AIDS Hotline at 1-800-541-AIDS (English) or 1-800-233-7432 (Spanish). Visit <http://www.thepointny.org/> to find Syringe Exchange places near you.
2. At a drug store: In New York State, the Expanded Syringe Access Program (ESAP) allows registered drugstores to sell up to ten syringes at a time, without a prescription, to adults 18 years or older. To find ESAP pharmacies, and for answers to questions about HIV/AIDS and safe syringe and needle disposal, call the New York State HIV/AIDS Hotline at 1-800-541-AIDS (English) or 1-800-233-7432 (Spanish).
3. From your healthcare provider: Under ESAP, health care facilities as well as doctors and other health care providers can prescribe syringes and provide syringes without a prescription. Talk to your doctor about ways you can get access to sterile needles and syringes.

To find pharmacies that participate in the ESAP Program, visit: https://www.health.ny.gov/diseases/aids/consumers/prevention/needles_syringes/esap/provdirect.htm

9. What can people who are living with HIV do to avoid passing the virus to others?

There are a number of steps people can take to avoid passing HIV to others. To avoid passing the virus to others, people living with HIV are encouraged to see their healthcare provider regularly. When someone stays in healthcare and takes their medication, that person will have a higher likelihood of being virally suppressed (also known as undetectable). Undetectable means the virus is present at such low levels that it is not detected in blood. Having a consistently undetectable viral load for 6 months and beyond greatly lowers your chance of transmitting the virus to your sexual partners who are HIV-negative. Because of U=U (undetectable = untransmittable), we now know the risk of sexual transmission of HIV from someone with a fully suppressed HIV viral load is negligible, meaning so small or insignificant it is hardly worth considering. Depending on the comfort level of each partner, other prevention methods such as use of condoms or PrEP may be used (**for more information on PrEP, see question 14**).

10. What can I do if I think I was exposed to HIV?

New York State Department of Health's HIV Clinical Guidelines recommend non-occupational post exposure prophylaxis (nPEP or PEP) at certain times when a person is potentially exposed to HIV, for example when a condom breaks, during a sexual assault, with sharing needles or works, or during other exposures to blood or other potentially infected body fluids. PEP involves taking a combination of HIV medicines for 28 days. PEP should be started as soon as possible, ideally within 2 hours of exposure. Decisions regarding initiation of PEP beyond 36 hours but no longer than 72 hours after the exposure are made on a case by case basis, keeping in mind that the medicine is most effective the closer it can be taken to the exposure.

The DOH has a fact sheet that a person who has been exposed to HIV can use as a reference. You can find that fact sheet at: https://www.health.ny.gov/diseases/aids/general/prep/docs/fact_sheet.pdf

If you think you were exposed to HIV, talk to a medical professional about PEP as soon as possible. You can call the NYS or NYC PEP hotline:

Outside NYC: 844-PEP4NOW (844-737-4669)

In NYC: 844-3-PEPNYC (844-373-7692)

For PEP to work, every dose of each medicine prescribed must be taken, for the full period of time. PEP can be expensive and insurance coverage may vary, but options for payment assistance can be found on the NYSDOH website at: https://www.health.ny.gov/diseases/aids/providers/standards/docs/payment_options_npep.pdf

Payment is available for sexual assault victims. Talk to your healthcare provider or an emergency room doctor right away if you think you've recently been exposed to HIV.

Testing

11. Why is HIV testing important?

Testing is important because it is the only way to know if you have HIV. The sooner that HIV is detected, the sooner medical care can begin. Getting early HIV treatment will help keep you healthy and prevent HIV from affecting how long you live or how well you feel.

12. How does HIV testing work?

Most people who are living with HIV will have a reactive test, meaning the test found evidence of HIV, within one month of transmission. The period of time after transmission, before the HIV test turns reactive is called the “window period.” When transmission first occurs, the virus begins to reproduce and the body makes antibodies to fight HIV. When enough virus is present or antibodies are developed, the HIV test will be reactive. Most people living with HIV will develop enough antibodies or have enough virus present to be detected by the latest testing technology two to four weeks after the exposure. Virtually all cases of HIV can be detected by three months after transmission occurs.

For a standard HIV test, a blood or oral fluid sample is taken and sent to a laboratory. You will need to call or come back about a week after the test to get your test result. At some clinics and doctors’ offices, you can get a rapid HIV test, which can give you a preliminary result that day. The test takes about 20 minutes. If your rapid HIV test is reactive (meaning HIV virus or antibodies were found), you will need additional testing that is sent to a laboratory. While you are waiting for the final test result, you should practice HIV prevention techniques to protect your partners. When you get your final test result, you will receive information about what the result means, and linkage to care as necessary.

A **home HIV test kit** is sold over-the-counter at pharmacies and other stores. With the home test kit, you take a finger-stick blood sample and send it to a laboratory. Later, you call to get the test result over the phone, using an anonymous code number. Follow up with a healthcare provider if have a reactive test or have any questions regarding your result.

If you have a negative test result, please see question number 14 for more information.

If you have a reactive test result, please see question number 15 for more information.

To find out more about getting tested, call your healthcare provider, 1-800-541-AIDS (English)/ 1-800-233-7432 (Spanish) or visit: <https://campaigns.health.ny.gov/BeyondStatus>.

13. Where can I get an HIV test?

Many people have a primary care provider that they see regularly. At least once in the course of regular medical care, you should be offered an HIV test if you are over the age of 13. If you are not offered one, you can ask for an HIV test.

If you would like an HIV test but do not have a regular primary care provider, there are many places you can go for an HIV test. You can make an appointment with a primary care doctor, go to a community based organization that offers HIV testing, go to your local health department, family planning clinic, or even find a mobile van at a community event where HIV testing is offered. You can find out about places that offer HIV testing at <https://campaigns.health.ny.gov/BeyondStatus>.

14. How often should a person be tested?

Health care providers should test everyone at least once as part of routine health care. However, if you continue having unprotected sex or sharing injection drug equipment, you should get tested at least once a year. Sexually active gay and bisexual men may benefit from more frequent testing (e.g., every 3 to 6 months). If you think you have had a potential exposure to HIV, you should consider PEP and get tested as soon as possible. If you receive a negative test result, you may want to consider PrEP (please see question #13 for more information on PrEP)

15. What does it mean to have a negative test result?

A negative test result generally means you do not have HIV. However, if you have had a recent exposure you may be in the “window period.” The window period is the period of time between someone potentially being exposed to HIV and when the test is able to detect it. If the first result comes back negative and there is still concern, getting tested again 3 months after the last possible exposure can help you to be sure.

People who have a negative test result but would like to reduce the risk of HIV may want to consider Pre-Exposure Prophylaxis (PrEP). PrEP is a daily pill that people take so they can reduce their worry about acquiring HIV, and keep HIV from entering your body.

You may want to consider taking PrEP if you are:

- A gay or bisexual man who has unprotected sex
- A transgender woman who has sex with men
- In a relationship with a person who is living with HIV
- Someone who has condomless sex with multiple partners
- A person who has been diagnosed with an STD in the past 6 months

- People who have injected drugs in the past six months and have shared needles or works
- Considering getting pregnant and have a partner who is living with HIV

If taken daily, PrEP works very well at preventing HIV. People wishing to take PrEP need to see their healthcare provider for a prescription, and follow up with testing every 3 months. Many insurance plans, including Medicaid and private health insurances will cover the cost of PrEP. Visit the DOH website for information about how to pay for PrEP, including the DOH PrEP-Assistance Program (PrEP-AP) at: https://www.health.ny.gov/diseases/aids/general/prep/prep-ap_provider.htm

Programs that help pay for PrEP include:

- Gilead medication assistance program for people who do not have health coverage, visit <http://www.truvada.com/truvada-patient-assistance> or call 1-855-330-5479.
- Co-pay Coupon Card from the drug manufacturer if you have health coverage but the amount of medication co-pay would present a financial challenge, you may be eligible for one. Visit <http://www.gileadcopay.com/> or call 1-877-505-6986 for more information.
- Patient Advocate Foundation Co-Pay Relief Fund- Provides financial assistance to financially and medically qualified patients for co-payments, co-insurance, and deductibles. Patients, their medical providers, or their pharmacists may submit applications 24 hours a day via the Online Application Portal at www.copays.org/gateway or Monday - Friday 8:30am – 5:30pm EST via phone at (866) 512-3861.
- Partnership for Prescription- Designed to help uninsured Americans get the prescription medicines they need at no or low cost. Visit www.pparx.org, enter the names of the medicines taken and answer a few questions to determine what options are available. Call the toll-free number if there is difficulty with the web site. Call toll-free 1-888-4PPA-NOW (1-888-477-2669) for a trained specialist to answer questions and help with the application.
- PrEP-AP – A NYS Health Department program to assist people without insurance or who are underinsured with the cost of health care appointments or lab work needed for people taking PrEP

16. What does it mean to have a test that results in an HIV diagnosis?

If you have a test result that results in an HIV diagnosis, you will receive post-test education about the meaning of the test result and the importance of health care. HIV treatment is effective, easy to take and has few or no side effects. The HIV testing provider will schedule an appointment for HIV care on the spot.

If you a person living with HIV, it will be important to reduce the risk of passing the virus to others.

The HIV testing provider will talk to you about the importance of notifying partners of possible exposure to HIV and the importance of HIV testing. The provider will report known partners and spouses to the Department of Health. However, persons who are diagnosed with HIV can choose from the following options on how they would like to have their partners informed that they have been exposed to HIV:

- A counselor from the New York State Health Department PartNer Assistance Program (PNAP) or the Contact Notification Assistance Program (CNAP) in New York City can tell partners without revealing the identity of the person
- People can tell their partners with the help of their healthcare provider or PNAP/CNAP counselor
- People can tell their partners themselves

Help from PNAP/CNAP is free. For more information, call the New York State Department of Health HIV/AIDS Hotline (see the **Resources** section). In New York City, call CNAP at 1-212-693-1419.

Importance of Health Care and Treatment

17. How does HIV affect a person's health?

The signs and symptoms of early/ acute HIV can begin 2 to 4 weeks after transmission occurs with HIV. During the initial weeks after transmission, about 80% of people will develop symptoms similar to the flu. This may include things like fever, fatigue, sore throat, headaches and swollen lymph nodes. Although many of symptoms are similar, there are some differences to look for between HIV and the flu. Early HIV may cause rash or mouth sores. Flu signs that differ may be nasal congestion, cough and sneezing. Symptoms can last for just a few days or weeks, and in rare cases for several months. After that, the person may feel and look fine for some time. HIV testing is the only way to know if a person has HIV.

If HIV is left untreated, over time it will seriously damage the person's immune system and leave him or her open to life-threatening infections and even death. Early in the epidemic, before our current treatments were available, most people living with HIV died within 12-15 years. Today, once a person has a reactive (meaning the test found evidence of HIV) test result, he or she will be linked to a health care provider who will provide care and prescribe medication they need. With treatment, people living with HIV can stay healthy and live life fully. HIV is no longer a death sentence. Now people living with HIV are living as long as those who do not have HIV.

18. What is the treatment for HIV?

HIV is treated by taking a combination of medications. The different medications fight the virus at different stages. The health care provider will use a lab test called a genotype test or resistance test to determine the most effective treatment regimen for the patient. The good news is that pharmaceutical companies combine the different antiretroviral medications into one pill. This means that for many patients, treating HIV may be as simple as taking one pill, once a day.

It is important to seek treatment for HIV as early as possible. Getting early HIV treatment will help keep people living with HIV healthy and prevent HIV from affecting how long they live or how well they feel. The pills have either no side effects or manageable side effects. Taking the medications consistently is the most important key to staying healthy and feeling well. Once a person begins to feel well, that does not mean they should stop taking their medicine. In order for HIV medication to be the most effective, it should be taken every day even if the person feels healthy. When people living with HIV who see their healthcare provider regularly and take their medication every day, there is a very good chance that they will become virally suppressed. Viral suppression, sometimes known as being undetectable, is an important goal of treatment. Viral suppression means the amount of virus in the person's blood is below the level the test can identify.

If a person living with HIV doesn't take their medications regularly, the treatment won't work as well and the amount of HIV in your body will increase. That is called having a detectable viral load. This will eventually lead to damage to the person's immune system and greater chances of becoming ill. If people living with HIV don't take their medication regularly, it also can lead to what is called drug resistance. This means the virus can get around the medication and the healthcare provider may have to prescribe a new treatment plan that might be more complicated to take, or possibly have a greater risk of side effects.

19. How can a person get help paying for HIV treatment?

If a person already has health insurance, the insurance will most likely cover the cost of the medications used to treat HIV. Depending on the health care plan, the person may still have co-pays. If a person does not have health insurance, there are options to help provide the medication at no cost or at a reduced cost.

The New York State Department of Health, AIDS Institute offers five programs known as the *HIV Uninsured Care Programs* to provide access to health care for people with (or at risk of) HIV who are uninsured or underinsured:

- **ADAP** (AIDS Drug Assistance Program) pays for medications used to treat HIV/AIDS

- **ADAP Plus** (Primary Care) pays for medical visits and lab tests at enrolled clinics, hospitals, and private doctors' offices
- **HIV Home Care Program** pays for home health care
- **APIC** (ADAP Plus Insurance Continuation) pays the premium for cost-effective health insurance.
- **PrEP-AP** (Pre-Exposure Prophylaxis Assistance Program) pays for medical and lab testing associated with the use of Pre-exposure Prophylaxis medications to prevent HIV.

How to apply:

- Phone: 1-800-542-2437
- TDD: 1-518-459-0121
- Staff is available to answer your questions. Hablamos Española.
- Internet: www.health.ny.gov/diseases/aids/resources/adap/index.htm

20. How can I tell if my HIV treatment is working?

A person can tell if his or her HIV treatment is working by looking at the results of the blood tests that measure viral load and the health of the immune system. An HIV treatment regimen is considered effective if: it's able to control HIV to the point that the virus is "undetectable"; or the CD4 count is close to or within the normal range. Even when HIV treatment is effective, the virus is still present, but the viral load level is low enough that HIV is considered controlled.

Human Rights, Stigma and Confidentiality

21. Are there laws in New York State that protect the confidentiality and human rights of people living with HIV?

Yes. New York State Public Health Law (Article 27F) protects the confidentiality and privacy of anyone who has been:

- tested for HIV
- exposed to HIV
- diagnosed with HIV or HIV/AIDS-related illness
- treated for HIV/AIDS-related illness

Discrimination against persons living with HIV in the areas of employment, housing, public accommodation, health care, and social services is prohibited by law.

The Americans with Disabilities Act (ADA) gives Federal civil rights protections to individuals with disabilities similar to those provided to

individuals on the basis of race, color, sex, national origin, age, and religion. People living with HIV, both symptomatic and asymptomatic, are protected by the ADA because HIV is considered a disability. The ADA also protects persons who are discriminated against because they have a record of or are regarded as having HIV, or they have a known association or relationship with an individual who has HIV. Persons who are discriminated against because they are regarded as being a person living with HIV are also protected. For example, the ADA would protect a person who is denied an occupational license or admission to a school on the basis of a rumor or assumption that he or she has HIV or AIDS, even if he or she does not, as protected by law.

The Fair Housing Act (FHA) prohibits discrimination against individuals with disabilities, including HIV or AIDS. The FHA prohibits discrimination in the sale or rental of housing (such as apartments, houses, mobile homes, nursing homes, assisted living centers, group homes, student housing, and homeless shelters), and in other residential real estate transactions.

22. What can we do to reduce stigma against people living with HIV?

There are many ways people can fight HIV stigma in our lives and in our community, whether you are a person living with HIV or HIV-negative. In many cases, stigma around HIV exists alongside other forms of stigma and discrimination, such as: discrimination against people who are lesbian, gay, bi-sexual (called homophobia); discrimination against people who are transgender (transphobia); and, discrimination or stigma directed at people who use drugs. Ageism, or negative feelings toward people who are young or old, can also play a role in HIV stigma. To effectively address HIV stigma, it is important to address homophobia, transphobia, stigma directed to people who use drugs and ageism. Reducing stigma around HIV is about promoting a community where people are accepted for who they are and we celebrate our similarities and differences.

Here is some idea for how to address stigma:

- Challenge attitudes, beliefs and behaviors that contribute to HIV stigma. Don't be a silent witness to it when it happens around you.
- Break the silence around HIV in your community. Acknowledge HIV just as you would any other chronic illness.
- Get information about HIV testing and know your own HIV status.
- Treat people living with HIV with compassion and acceptance.
- Learn supportive ways to react when someone tells you they are living with HIV.
- Educate your community that HIV is not transmitted through casual contact.

- Avoid using language that overtly stigmatizes others.
- Treat people living with HIV as you would treat anyone else: with respect, empathy, and compassion.

Check out the HIV Stops with Me Campaign at <http://hivstopswithme.org/>. This is a multifaceted, national social-marketing campaign that aims to prevent the spread of HIV, promote the benefits of HIV treatment and reduce stigma associated with the disease. The campaign features real people living with HIV talking about any issues they may face.

Glossary

This glossary includes definitions of different terms used throughout this document. At the end of each definition in parenthesis you will find the name or acronym of the source organization for the definition. Visit the organization's website for more information.

Acquired Immunodeficiency Syndrome (AIDS): The most advanced phase of infection with HIV (human immunodeficiency virus) in which the immune system is weakened. The person becomes more susceptible to a variety of infections (called opportunistic infections) and other conditions such as cancer. A diagnosis of AIDS is made based on clinical criteria and/or the results of blood tests. Specifically, AIDS is diagnosed when a person living with HIV has a CD4 count less than 200 cells/mm³ or has an AIDS-defining condition. (NYC DOHMH)

Ageism: Discrimination of someone based on a person's age

Antiretroviral (ARV): Means "against retrovirus"; HIV is a retrovirus. An antiretroviral is a drug that controls the retrovirus. (NYC DOHMH)

Antiretroviral Therapy (ART): Antiretroviral therapy (abbreviated as ART): Treatment with drugs designed to control HIV. For HIV therapy to be successful over time, the initiation of ART should involve both the selection of the most appropriate regimen and the acceptance of the regimen by the patient, bolstered by education and adherence counseling. All are critical in achieving the goal of durable and complete viral suppression. Discussion of ART should occur at the start of care for all HIV patients, regardless of CD4 count. The clinician and patient should discuss the benefits of early ART and individual factors that may affect the decision to initiate, such as patient readiness or reluctance and adherence barriers. (NYS HIV Guidelines Program)

CD-4 count: A CD4 count is a lab test that measures the number of CD4 T lymphocytes (CD4 cells) in a sample of your blood. In people living with HIV, it is the most important laboratory indicator of how well your immune system is working and the strongest predictor of HIV progression. (AIDS.gov)

Gay: A person who is emotionally and/or physically attracted to some members of the same gender. "Gay" often refers to a male-identified person who is emotionally and/or physically attracted to some other males. "Gay" should not be used as an umbrella term to refer to all lesbian, gay, bisexual and transgender people; the term "LGBT" is more accurate and inclusive. (GLSEN)

Genotype Test: look directly at the genetic material of the HIV in your blood and give you information about the HIV drugs your virus is resistant to, they are the most common and widely used resistance test. (AIDS.gov)

Hepatitis C Virus (HCV): HCV is usually transmitted through blood and rarely through other body fluids, such as semen. HCV progresses more rapidly in people coinfecting with HIV than in people with HCV alone. (AIDSinfo)

Human Immunodeficiency Virus (HIV): HIV is a retrovirus that attacks the body's immune system, making people who have transmitted HIV potentially vulnerable to other infections and diseases. If untreated with antiretroviral medications, HIV can progress to AIDS (see above). People with either HIV or AIDS can lead healthy lives if they receive ART and appropriate routine medical care. (NYC DOHMH)

HIV Antibody Test: The most common test used to diagnose HIV. It does not test for the presence of HIV, but for the presence of antibodies against the virus. The test can be conducted with a blood sample or oral fluid (cheek or gum swab). Urine tests are also available but are not as effective at detecting antibodies. Typical antibody test results are available in about a week; rapid HIV antibody test results are available within half an hour. In July 2012, the FDA approved the first over-the-counter home HIV test kit. See also EIA/ELISA. (NYC DOHMH)

HIV Negative: A person who is HIV negative is someone who is not living with HIV. An HIV negative test result is one where no HIV antibodies or antigens were discovered in the sample.

HIV Positive: A person who is HIV positive is someone who is living with HIV. A series of laboratory tests have resulted in the diagnosis of HIV.

Lesbian: A person who is female-identified and who is emotionally and/or physically attracted to other females. (GLSEN)

LGBTQ: An umbrella term referring to people who identify as lesbian, gay, bisexual, transgender, queer and/or questioning. The acronym can also include additional letters, in reference to other identities. (GLSEN)

Outercourse: Can mean different things to different people. For some people, outercourse is any sexual activity without vaginal intercourse. For others, it's sexual activity with no penetration at all — oral, anal, or vaginal. (Planned Parenthood)

Perinatal HIV: HIV transmission from mother to child, which can happen during pregnancy, labor, delivery, and breastfeeding. (CDC)

Post-Exposure Prophylaxis (PEP): HIV antiretroviral medication taken less than 36 hours after possible exposure to HIV to reduce the chance of having a test that comes back as having a diagnosis of HIV. For example, a person who is having sex and the condom breaks should seek a healthcare provider's advice on whether to take PEP. (NYSDOH)

Pre-Exposure Prophylaxis (PrEP): Pre-Exposure Prophylaxis (PrEP) is an HIV prevention method in which people who do not have HIV take a daily pill (HIV antiretroviral medication) to reduce their risk of becoming infected. Based on studies showing significant reduction in HIV acquisition among HIV-negative persons who use PrEP and receive a package of prevention, care and support services, the U.S. FDA approved combination anti-retroviral therapy (ART) for use as PrEP among sexually active adults at risk for HIV. (NYSDOH)

Reactive: the HIV test indicates that HIV antibodies were found in a blood or oral sample.

Risk Behavior: Activity that makes a person more susceptible or more likely to be exposed to harm. Because different activities have different levels of risk, activities are often called either high-risk or low-risk. (NYC DOHMH)

Sexual Health: Sexual health is having a feeling of wellness related to sexuality. It applies to people of all ages. Sexual health is physical, emotional, mental, and spiritual. It is a central element of human health. Sexual health is based on a positive, equal, and respectful approach to sexuality, relationships and reproduction. This is based on free choice and are without fear, violence, discrimination, stigma or shame. (NYS DOH AIDS Institute)

Sexual Orientation: The inner feeling of who a person is attracted to emotionally and/or physically, in relation to their own gender identity. Some people may identify as “asexual,” “bisexual,” “gay,” “lesbian,” “pansexual,” “queer,” “straight,” and many more. (GLSEN)

Sexually Transmitted Disease or Infection (STD or STI): Any disease or infection that is transmitted primarily through sexual contact. (NYC DOHMH)

Stigma: Stigma occurs when a person or a group of people are devalued because they are associated with a certain disease, behavior or practice. (ICRW)

T-cells: A class of immune system cells that play a major role in carrying out the activities of the immune system. Some T-cells are called Helper T-cells (or CD4 cells). (NYC DOHMH)

Terminal: predicted to lead to death, especially slowly; incurable. (Google)

Undetectable: When there is so little virus in an a person who is living with HIV's blood that it cannot be measured by viral load tests. An undetectable viral load is associated with better long-term health. The person is still HIV positive, but the risk of infection is lower and the chances of passing the virus to a partner is greatly reduced. (NYSDOH)

Viral load: A measure of HIV in the blood. Nucleic acid amplification test (NAAT) tests for viral load, not for the presence of HIV antibodies. (NYC DOHMH)

Resources

HIV/AIDS Hotline Number

English: 1-800-541-2437

Spanish: 1-800-233-7432

Hearing Impaired Relay System:

Call 1-800-421-1220

and ask the operator to call 1-800-541-2437

Condom Access

New York State Condom Access Program

(organizations only)

nyscondom@health.ny.gov

New York City Condoms

(New York City Only)

Dial 311

Also available at:

<https://www.nyc.gov/site/doh/health/health-topics/condom.page>

Statewide Hotline

(Must be aged 18 and above, living in NYS to receive condoms)

1-800-541-2437

HIV Counseling Hotline

(Must be age 18 and above, living in NYS to receive condoms)

1-800-872-2777

Condom Program

<http://www.health.ny.gov/diseases/aids/consumers/condoms/nyscondom.htm>

Condom Availability Program Rubric and Assessment

<http://www.p12.nysed.gov/sss/documents/NYSED-CAP-update.4.25.14.pdf>

Condoms for Schools

<https://www.health.ny.gov/diseases/aids/consumers/condoms/nyscondom.htm>

Confidentiality / Discrimination

New York State Confidentiality Hotline
1-800-962-3934

Legal Action Center
(212) 243-1313

Department of Justice
(Americans with Disabilities Act)
www.ada.gov/HIV

ADA Information Line
1-800-514-0301

Educational Materials about HIV/ AIDS

New York State Department of Health
(free of charge)
(518) 474-3045

Order form available at:

https://www.health.ny.gov/forms/doh_publication_order_form.pdf

CDC list of AIDS defining illnesses

<https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5710a2.htm>

Ending the Epidemic (ETE)

Ending the Epidemic Dashboard
www.etedashboardny.org/

ETE Blueprint Summary

https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/blueprint_summary.pdf

NYSDOH ETE Information

https://www.health.ny.gov/diseases/aids/ending_the_epidemic/

HIV General Information

Reduce Stigma

<http://hivstopswithme.org/>

Faith-Based Ministries and Services Resource Directory

https://www.health.ny.gov/diseases/aids/consumers/faith_communities/directory_instruction.htm

HIV Basic Facts

http://www.health.ny.gov/diseases/aids/consumers/hiv_basics/index.htm

HIV Epidemiology Reports

<https://www.health.ny.gov/diseases/aids/general/statistics/annual/>

HIV History

<https://www.aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline/>

Staying Healthy for Life: A resource Guide for People with HIV

<https://www.health.ny.gov/publications/0249.pdf>

HIV Testing

New York City Testing Resource

311

NYS Testing Locations Near You

<https://campaigns.health.ny.gov/BeyondStatus>

New York State Department of Health HIV/AIDS Hotline

1-800-541-AIDS (2437) (English)

1-800-233-SIDA (7432) (Spanish)

<https://campaigns.health.ny.gov/BeyondStatus>

HIV Counseling Hotline

Mon - Fri, 4 p.m.- 8 p.m.

Sat - Sun, 10 a.m.- 6 p.m.

1-800-872-2777

Human Rights/Discrimination

Legal Action Center

(212) 243-1313

New York State Division of Human Rights

1-888-392-3644

New York City Commission on Human Rights

(212) 306-7450

Insurance

HIV Uninsured Care Program (“ADAP”)

1-800-542-2437 (in state)

(518) 459-1641 (out of state)

ADAP@health.ny.gov

Needle/ Syringe Exchange/Opioid Overdose

Syringe Disposal Sites/Medication Drop off points

<http://www.thepointny.org/>

Opioid Overdose Information

1-800-692-8528

Opioid Overdose Prevention Programs Directory

<https://providerdirectory.aidsinstituteny.org/>

Safe Injection Practices

<https://harmreduction.org/issues/safer-drug-use/facts/>

Newborn Regulations and Screening

Specimens and Guidance on testing
(518) 474-2163

New York State Department of Health
HIV/ AIDS information hotline
1-800-369-2437

Partner/Spousal Notification

New York State HIV/AIDS Hotline
1-800-541-AIDS (English)
1-800-233-SIDA (Spanish)
1-800-369-AIDS (Deaf)

New York City (New York City Residents Only)
(212) 693-1419

PrEP/PEP

General Information
1-800-541-AIDS (2437) (English)
1-800-233-SIDA (7432) (Spanish)
<https://campaigns.health.ny.gov/BeyondStatus>

New York State Department of Health
Clinical Education Initiative
For Medical Providers to discuss PrEP Management
1-866-637-2342

PrEP Assistance Information
1-800-542-2437

PrEP Resources
PrEPforsex.org

PrEP Provider Directory
https://www.health.ny.gov/diseases/aids/general/prep/provider_directory.htm

Smoking Cessation Resources

NYS Quitline
1-866-697-8487

Tobacco Control Program
https://www.health.ny.gov/prevention/tobacco_control/program_components.htm

Substance Use Treatment

New York State Office of Alcoholism and Substance Abuse Services (OASAS)

Available 7 days/ 24 hours

[1-877-8-HOPENY](tel:1-877-8-HOPENY)

[1-877-846-7369](tel:1-877-846-7369)

LIFENET

New York City Only, 24 hours a day, 7 days a week.

LIFENET also offers confidential help with depression and other mental health problems.

[1-800-543-3638](tel:1-800-543-3638)

Training for Health and Human Services Providers

Training for Human Services Providers

[\(518\) 474-3045](tel:518-474-3045)

www.hivtrainingny.org

Training for Clinicians

[1-866-637-2342](tel:1-866-637-2342)

<https://www.ceitraining.org/>

Youth

Act Youth Network

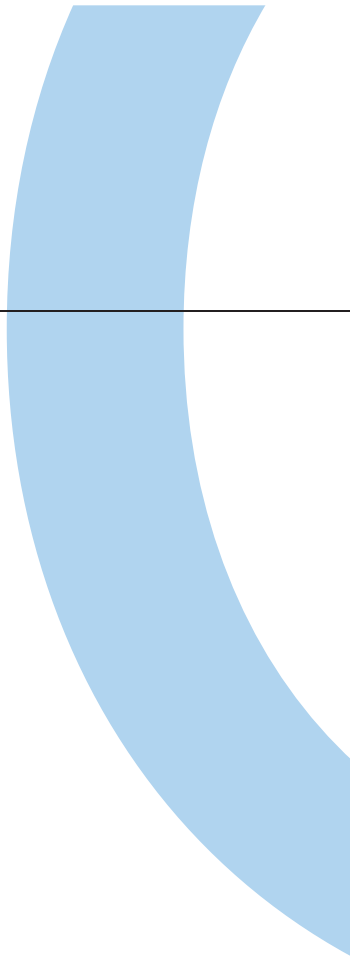
<http://www.nysyouth.net/>

New York State Youth Sexual Health Plan

http://www.health.ny.gov/community/youth/development/docs/nys_youth_sexual_health_plan.pdf

Take Control!

http://www.nysyouth.net/sexual_health/



**Department
of Health**