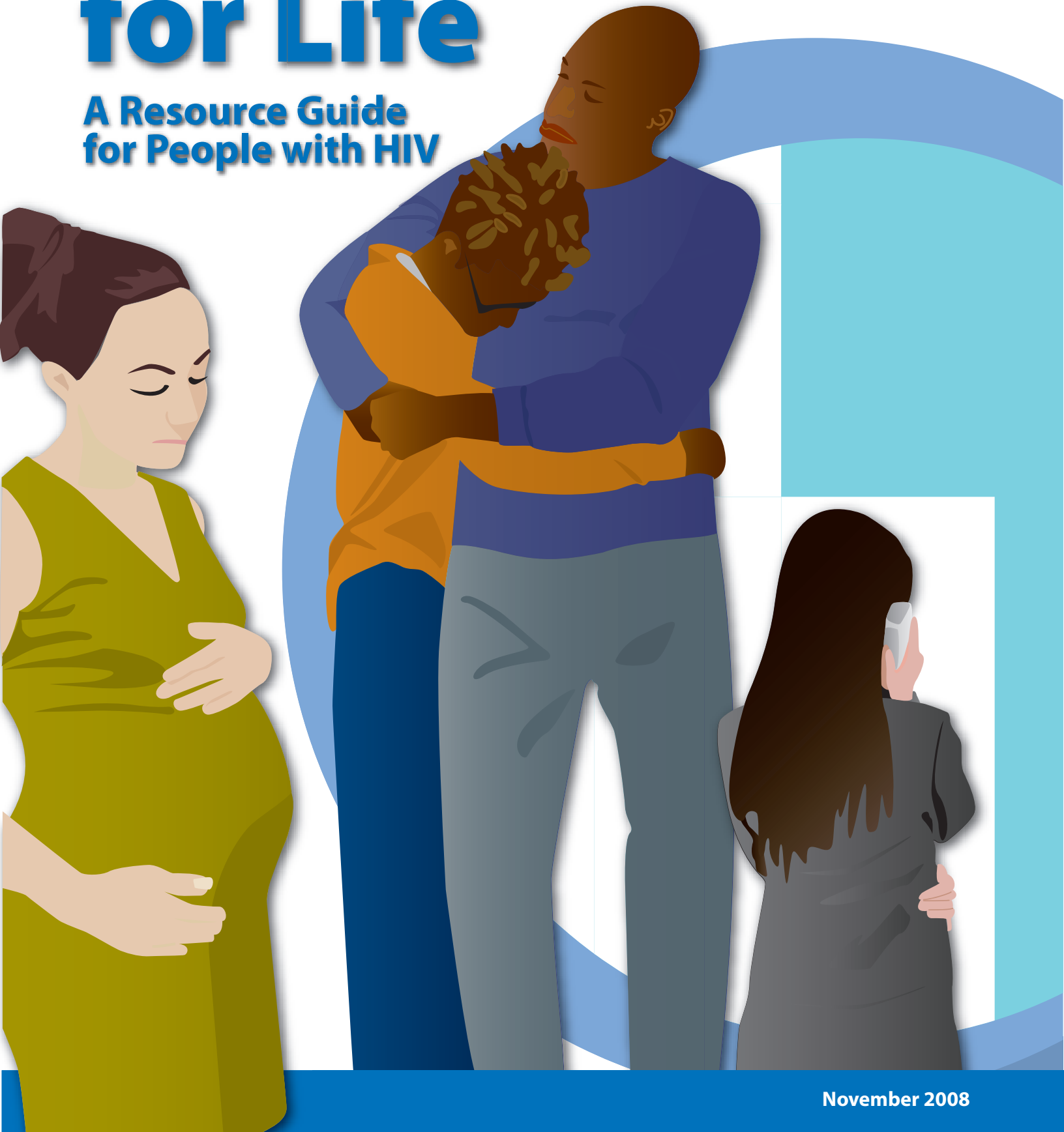


Staying Healthy for Life

**A Resource Guide
for People with HIV**



Staying Healthy for Life

A Resource Guide for People with HIV

This booklet explains the steps you can take to stay healthy after you are diagnosed with HIV. Two key early steps are seeing a doctor and getting health (medical) insurance.

Having HIV does not mean you have AIDS or that you will die. HIV is like many other illnesses — you can get medical treatment for it and stay healthy. The key is to see a doctor right away and not wait until your HIV gets worse.

This booklet tells you about:

- Why it is so important to go to a doctor or a health care clinic right away, even if you do not feel sick.
- Health insurance. There are special programs in New York City and New York State for people with HIV who cannot afford their medical bills.
- HIV case managers. They can help you get the services you need.
- How to protect yourself and others from HIV and other diseases.

If you are reading this on a computer, you will see website addresses written in blue. Click on those websites for more information. If you do not have a computer, go to page 15 for phone numbers you can call to learn more about living with HIV. Remember that New York City is part of New York State. If you live in New York City, you can get New York State services.

HIV = Human Immunodeficiency Virus

the virus that causes HIV infection.

AIDS = Acquired Immune Deficiency Syndrome

AIDS is the advanced stage of HIV disease, where a person's immune system breaks down and cannot defend the body from various forms of infection and cancer.

Part 1

What should I do right away after my HIV diagnosis?

Talk with someone you trust. Dealing with your HIV diagnosis can be stressful. It is normal to feel grief, anger, fear, depression, shame, and hopelessness. Talk with someone you trust who will listen to you and support you:

- A relative
- A close friend
- Clergy member
- Professional counselor
- Your doctor or health care provider.

Tell your partners you have HIV. If you had unprotected sex with or shared drug injection “works” with anyone, you may have infected them. They deserve to know this so they can be tested for HIV and get medical treatment if they test positive. Partner services programs can help you tell your partner or they can tell your partner for you.



For more information on **how to talk with your partners**, go to:



www.nyhealth.gov/diseases/aids/docs/9488eng.pdf

For a list of organizations in your area that provide **partner services**, go to:


www.nyhealth.gov/diseases/aids/resources/resource_directory/patient_resources_directory.htm

Part 2

Work with a doctor or healthcare provider

Don't wait until you are sick to find a doctor and get medical care. Make an appointment now to see a doctor or health care provider about your HIV diagnosis. Try to find someone who:

- Has experience treating people with HIV.
- Listens to your needs and concerns and responds to them.
- Has an office that is not far from where you live.



HIV case manager

Someone who works with HIV-positive people all the time and knows a lot about HIV services. They help you find the HIV medical care, health insurance, and other services you need.

HIV specialist

A doctor or health care provider who is specially trained to treat HIV and who knows the latest HIV treatments and medicines.

Find an HIV specialist doctor or healthcare provider. If your doctor or health care provider does not have experience treating people with HIV, ask them to help you find an HIV specialist. HIV specialists focus on helping people with HIV/AIDS. They know more about new HIV treatment and HIV medicines. Find a provider you are comfortable with, who listens to your needs and explains things well.

If you can't find an HIV specialist right away, make an appointment with a regular doctor or health care provider for now.

Part 2 Work with a doctor or healthcare provider

Keep all your medical appointments. Ask your HIV case manager or counselor for help keeping track of your appointments or getting transportation to them. See page 7 to learn more about working with a case manager.

Do not wait until you are sick to find a doctor and get medical care. Try to find a doctor or health care provider who is an HIV specialist, who works mainly with people with HIV/AIDS.

What happens when I first start seeing a doctor?

Physical exam and history. Your doctor will do a complete physical exam to see how HIV is affecting your body and to find any other health problems that might affect your treatment.

Measure the amount of HIV in your body. Medical tests can measure the amount of HIV in your body.

Look for other kinds of infection. Other infections can weaken your body, make your HIV worse, or prevent your treatment from working well. These infections include hepatitis, sexually transmitted diseases (STDs), tuberculosis (TB), and pneumonia or flu. You can get shots (immunizations) to prevent some of them.

Talk about HIV medicines. Your doctor will talk to you about HIV medicines. You may not have to start taking them right away.

For a list of **HIV medical service providers** in New York City and all of New York State, click here:

www.nyhealth.gov/diseases/aids/resources/resource_directory/patient_resources_directory.htm

See these booklets for more **information on HIV medicines:**



<http://www.nyhealth.gov/publications/9236.pdf>



<http://www.nyhealth.gov/publications/9408.pdf>

Part 2 Work with a doctor or healthcare provider

Drug or alcohol problems. Heavy drinking or drug use can get in the way of your HIV care. Now is a good time to get help for these problems. Getting clean can improve your overall health and help you focus on your HIV care.

Mental health problems. Depression, anxiety, and other mental health problems can slow down your progress and make you feel worse about having HIV. Counseling and medicines can help.

You have a right to the best health care possible. If you are not pleased with the doctor you choose, you can switch to another doctor.

▶ These websites have important information about **health care for HIV-positive people:**

<http://www.gmhc.org/policy/benefits.html>

<http://www.projectinform.org/info/>

<http://www.cdc.gov/hiv/resources/brochures/livingwithhiv.htm>

Part 3

Work with an HIV case manager

When you go to a social services agency, you usually get a case manager. If you have HIV, it is better to have an HIV case manager. He or she can help you get health care, health insurance, and other services you need to stay healthy. They work only with people who have HIV and understand what you are going through.

Find an HIV case manager and an HIV specialist doctor or health care provider as soon as you can. They are professionals who work only with people who have HIV.

For more information on **case management**, go to:



www.nyhealth.gov/publications/9588.pdf

Go to this map to find the **case management services** nearest you:

www.nyhealth.gov/diseases/aids/resources/resource_directory/patient_resources_directory.htm



Part 4

How to find health (medical) insurance

Now that you've gotten into health care, you may need to figure out a way to pay for it—even if you do not need HIV medicines right away. There are government programs and insurance that can help you pay for medical tests and other health care you need right away. Figuring out how to get help can be complicated. Ask your HIV case manager or counselor to explain these programs and help you apply for them. Here are some common types of programs and insurance:

Private insurance. If you can afford it, private insurance can work well. A private insurance company can decide what services it covers and how much it pays the provider for those services. The company cannot deny you insurance because you have HIV.

Employer health insurance. Some employers provide insurance through managed care plans. Some managed care plans may not cover all the services you need. Talk with your case manager or counselor about what HIV services you might need. Then pick the managed care plan that covers the most services.

Even if you don't need to take HIV medicines right away, the HIV Uninsured Care Programs (ADAP/ADAP Plus/Home Care and APIC) and HIV Special Needs Plans (SNPs) can help you pay for medical care and medicines.



Part 4 How to find health (medical) insurance

Government Insurance Programs

Medicaid. Medicaid is a medical insurance program for New York State residents who cannot afford to pay for medical care. Medicaid covers many of the health care and medical services you may need. You may qualify for Medicaid if you:

- Have large medical bills.
- Receive Supplemental Security Income (SSI).
- Don't earn much money or have other resources (things you own).

If you live in New York City, you apply for Medicaid through the City of New York's Family Independence Administration. Outside of New York City, you apply for Medicaid through the local Department of Social Services (DSS). If you already have a caseworker, ask for help with the paperwork and forms you need to fill out. It may seem like a lot to go through, but stick with it. Your health is worth it.

Medicare. Medicare is a federal health insurance program that covers the cost of certain basic medical services for people 65 and older and some people with disabilities. If you become very sick from HIV/AIDS and are "disabled," or if you have received Social Security Disability Insurance (SSI) for 24 months, you may qualify for Medicare.

For more information on **Medicaid**, go to:

http://www.nyhealth.gov/health_care/medicaid/index.htm

For basic information on **Medicare**, go to:

<http://www.medicare.gov/Publications/Pubs/11082.pdf>



For facts about **Medicare Special Needs Plans**, see this booklet:

<http://www.medicare.gov/Publications/Pubs/pdf/11302.pdf>



Part 4 How to find health (medical) insurance

HIV Special Needs Plans. If you have HIV/AIDS and you get Medicaid, you can get a health care plan called an HIV Special Needs Plan (SNP, sounds like “snip”). An HIV SNP is a kind of Medicaid plan that provides special services for people with HIV or AIDS. It can also cover your children, up to age 19, even if they do not have HIV or AIDS. If you live in the New York City area, you have a better chance of getting a SNP.

HIV SNPs provide all the services that regular Medicaid covers. The medical services include:

- Office visits to your primary care provider.
- Physical exams and check-ups.
- Laboratory tests.
- Hospital care (in-patient care).
- Emergency room visits.
- Over-the-counter medicines and prescription medicines.
- Drug/alcohol abuse services and mental health services.

HIV Uninsured Care Programs. If you make too much money to qualify for Medicaid, or if you are waiting to get approved for Medicaid or Medicare, apply to the HIV Uninsured Care Programs. There are four programs that help people who do not have enough insurance or who have no health insurance at all. They are:

- AIDS Drug Assistance Program (ADAP) pays for HIV medicines and related medicines.
- ADAP Plus pays for “outpatient” medical care, like doctor’s visits and medical tests.
- HIV Home Care Program pays for care provided in your home if you are home bound.
- ADAP Plus Insurance Continuation Program (APIC) can help if you cannot afford health insurance or if you lose your job but want to keep your insurance.

For more information on **HIV Special Needs Plans**, go to:

<http://www.nyhealth.gov/diseases/aids/resources/index.htm>

For more information on **HIV Uninsured Care Programs and ADAP**, call **800-542-2437** or go to:

<http://www.nyhealth.gov/diseases/aids/resources/index.htm>

Part 4 How to find health (medical) insurance

Other government programs

Other government programs can help you pay for medical services and other services you may need. These programs include:

- Public Assistance
- Food Stamps
- Social Security Disability Assistance (“disability”)
- Services provided by the HIV/AIDS Services Administration (HASA) (only in New York City).

Your HIV information is private (confidential). Your doctor or health care provider cannot share your medical records or any information about your HIV infection. They need your written permission to share any information with a service provider or insurance company.



▶ These websites have more information about **government programs that provide medical care and health insurance for people with HIV/AIDS:**

<http://www.gmhc.org/policy/benefits.html>

<http://www.projectinform.org/info/>

<http://www.nyhealth.gov/diseases/aids/resources/index.htm>

▶ To learn more about **confidentiality**; go to:



<http://www.nyhealth.gov/diseases/aids/docs/doh-9192.pdf>

Part 5

Protect yourself and others from HIV and STDs

If you are sexually active — or if you still inject IV drugs — think about how to avoid passing HIV to others. HIV infection is like a chain from one person to another. You can break that chain and help others avoid infection. If you are sexually active:

Always wear a condom. Wear a latex male condom or polyurethane female condom every time you have sex.

Avoid getting re-infected with HIV. It is possible to be infected again if you are exposed to HIV again. Re-infection makes your HIV worse and slows your treatment progress.

Avoid STDs. When you have HIV plus another STD, you have more HIV in your semen or vaginal fluid. That makes it easier to pass the virus to someone else if you do not use a condom. Remember, you can get STDs through oral sex.

If you inject drugs:

- Use a new, sterile needle and syringe and sterile water each time you inject.
- If you reuse injection equipment (“works”), always use your own — don’t share your works with other people. Clean your needles and syringes with bleach and water.
- Get new needles and syringes from a drugstore without a prescription.

HIV infection is like a chain from one person to another. You can break that chain and help others avoid infection.

For step-by-step pictures on **how to use a male condom**, go to this website:

http://www.nyhealth.gov/publications/instructions_male_condom.pdf

For instructions on **how to use a female condom**, go to:



<http://www.nyhealth.gov/publications/9571.pdf>

This brochure has more facts about **sexually transmitted diseases**:



<http://www.nyhealth.gov/publications/3805.pdf>

This brochure has more information about **ESAP** and **syringe exchange programs**:



www.nyhealth.gov/diseases/aids/docs/doh-9405.pdf

Part 6

Special concerns for HIV-positive women

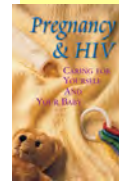
The biggest concern is pregnancy and childbirth. You can pass HIV to your baby while you are pregnant, during childbirth, or through breastfeeding.

- HIV medicines can stop HIV from going from your body into your baby. Your doctor will probably prescribe them for you and your baby.
- Ask your doctor about how HIV may affect your pregnancy and delivery.

Abnormal Pap smears. When your body has HIV, it is easier to get other viruses. Human papilloma virus (HPV) infects cells in the cervix and causes cervical cancer. A Pap smear can find these HPV cells. If your Pap smear is abnormal, your doctor may order a special test.

Talk with your doctor if you are pregnant, nursing a baby, or thinking about becoming pregnant.

This booklet has more facts on **HIV and pregnancy:**



<http://www.nyhealth.gov/diseases/aids/docs/9234eng.pdf>



Part 7

What can I do on my own to stay healthy with HIV?

Staying healthy with HIV is more than just taking medicines and going to doctor's appointments. A lot depends on you — and the effort you make to lead a healthy lifestyle.

Quit smoking. This is the biggest step you can take to improve your health. Ask your doctor about nicotine replacement and other ways to help you quit.

Do not drink alcohol or cut down on your drinking. HIV and some HIV medicines can harm your liver. Alcohol can also harm your liver.

Eat healthy foods. A good diet can help improve your energy and strength. Try to eat these foods every day: grains, fresh fruit and vegetables, dairy (milk) foods, and protein from meat, fish, or beans. Drink plenty of water and juices.

Exercise as much as you can. Exercise can help your body fight HIV, lower stress, and improve your mental health. Start out slow and do not overdo it if you feel tired or sick.

Get enough sleep/reduce stress. Make time for getting more sleep. Many people with HIV do special things to reduce stress — like yoga, meditation, or prayer.

HIV infection and HIV medicines you take can make you feel weak or sick. Be ready to change your eating and exercise routines if you do not feel well.

To learn more about
HIV and smoking, go to:



www.nyhealth.gov/diseases/aids/docs/doh-9533.pdf

Visit these websites for more
nutrition information:

<http://www.gmhc.org/health/nutrition.html>



<http://www.nyhealth.gov/diseases/aids/docs/9506.pdf>

Part 7 What can I do on my own to stay healthy with HIV?

Learn more about living with HIV

If you do not have a computer, you can call these hotline numbers for more information on living with HIV:

1-800-541-AIDS English

1-800-233-SIDA Spanish

You can listen to a counselor and ask any questions.

You do not have to give your name.

HIV/AIDS TTY Information Line:

1-212-925-9560

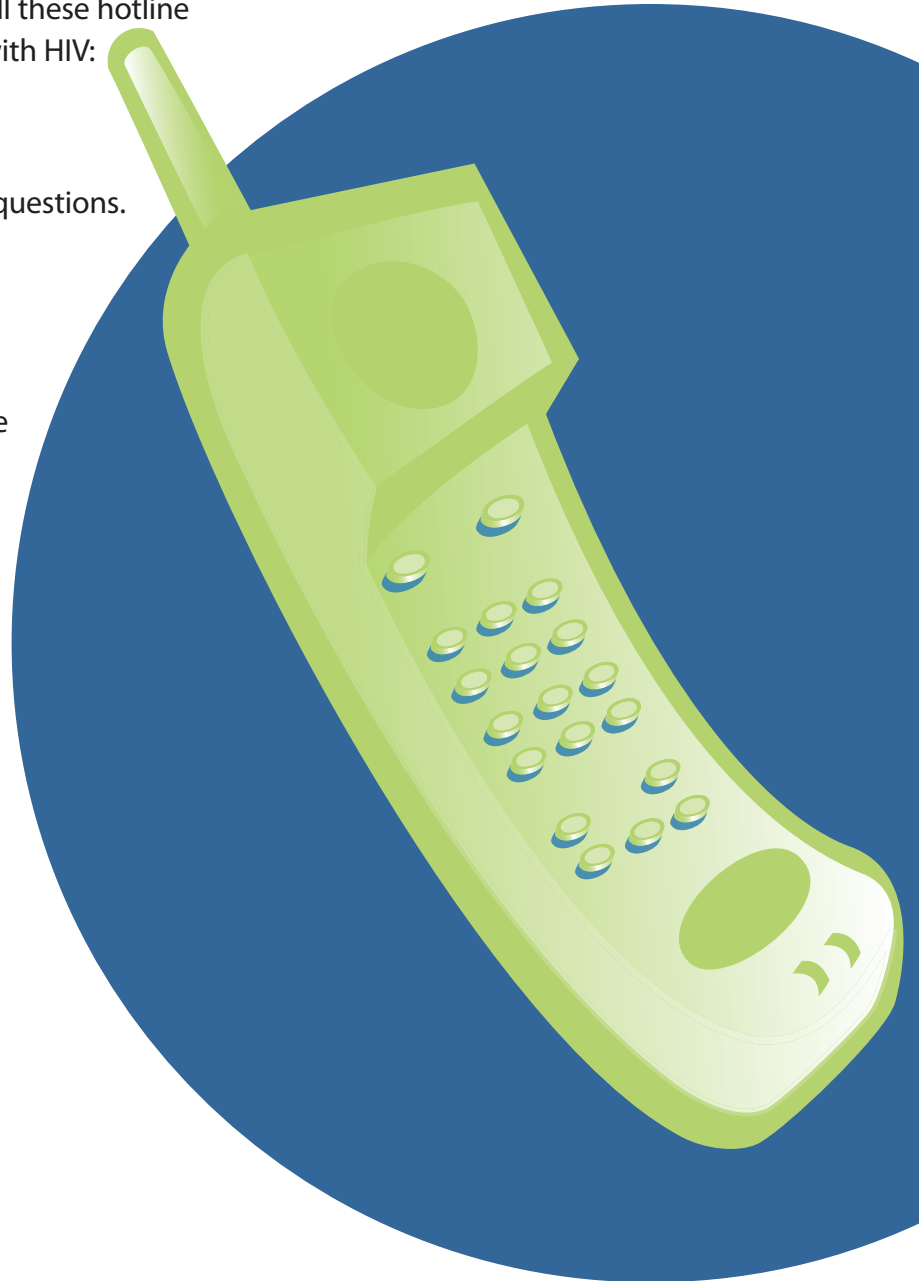
Deaf/Hard of Hearing callers can use the

New York Relay System:

Call **711** or **1-800-421-1220**

and ask the operator to dial

1-212-925-9560.



Web Links

Here are all the website addresses and publications in the same order that they appear in this booklet:

Partner notification:

www.nyhealth.gov/diseases/aids/docs/9488eng.pdf

Working with an HIV specialist:

<http://www.hivguidelines.org/admin/Files/policy/hiv-spec-pol/hiv-spec-policy.pdf>

Taking HIV medicines:

<http://www.nyhealth.gov/publications/9236.pdf>
<http://www.nyhealth.gov/publications/9408.pdf>

General health care information for HIV-positive people:

<http://www.gmhc.org/policy/benefits.html>
<http://www.projectinform.org/info/>
<http://www.cdc.gov/hiv/resources/brochures/livingwithhiv.htm>

Finding an HIV case manager:

www.nyhealth.gov/publications/9588.pdf

Medicaid:

http://www.nyhealth.gov/health_care/medicaid/index.htm

Medicare:

<http://www.medicare.gov/Publications/Pubs/pdf/11082.pdf>
<http://www.gmhc.org/policy/benefits/medicare.html>

HIV Special Needs Plans:

<http://www.nyhealth.gov/diseases/aids/resources/index.htm>

HIV Uninsured Care Programs:

<http://www.nyhealth.gov/diseases/aids/resources/index.htm>

General information about medical insurance:

<http://www.gmhc.org/policy/benefits.html>
<http://www.projectinform.org/info/>
<http://www.nyhealth.gov/diseases/aids/resources/index.htm>

Your right to confidentiality:

<http://www.nyhealth.gov/diseases/aids/docs/doh-9192.pdf>

How to use a male condom:

http://www.nyhealth.gov/publications/instructions_male_condom.pdf

How to use a female condom:

<http://www.nyhealth.gov/publications/9571.pdf>

How to avoid getting infected with STDs:

<http://www.nyhealth.gov/publications/3805.pdf>

HIV and injection drug use:

www.nyhealth.gov/diseases/aids/docs/doh-9405.pdf

HIV and pregnancy:

<http://www.nyhealth.gov/diseases/aids/docs/9234eng.pdf>

HIV and smoking:

www.nyhealth.gov/diseases/aids/docs/doh-9533.pdf

Nutrition, healthy eating, and HIV:

<http://www.gmhc.org/health/nutrition.html>
<http://www.nyhealth.gov/diseases/aids/docs/9506.pdf>