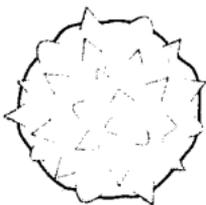
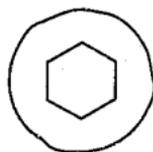


## The Immune System and HIV

The body's health is defended by its immune system. White blood cells called lymphocytes (B cells and T cells) protect the body from "germs" such as viruses, bacteria, parasites, and fungi. When germs are detected, B cells and T cells are activated to defend the body.



Lymphocyte



Human immunodeficiency virus—HIV

This process is hindered in the case of the acquired immunodeficiency syndrome (AIDS). AIDS is a disease in which the body's immune system breaks down. AIDS is caused by the human immunodeficiency virus (HIV).

When HIV enters the body, it infects special T cells, where the virus grows. The virus kills these cells slowly. As more and more of the T cells die, the body's ability to fight infection weakens.

A person with HIV infection may remain healthy for many years. People with HIV infection are said to have AIDS when they are sick with serious illnesses and infections that can occur with HIV. The illnesses tend to occur late in HIV infection, when few T cells remain.

### Where did HIV and AIDS come from?

We may never know where or how HIV and AIDS began. Many experts believe that AIDS was present in the United States, Europe, and Africa for several decades or longer before the earliest cases appeared in 1980 and 1981.

HIV was first identified in 1984 by French and American scientists, but the human immunodeficiency virus did not get its name until 1986.

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# Understanding HIV

## Purpose of this Booklet

Even before HIV causes AIDS, it can cause health problems. Learning about how the virus can affect your body and getting care early, before health problems worsen, can help you live longer and have fewer health problems.

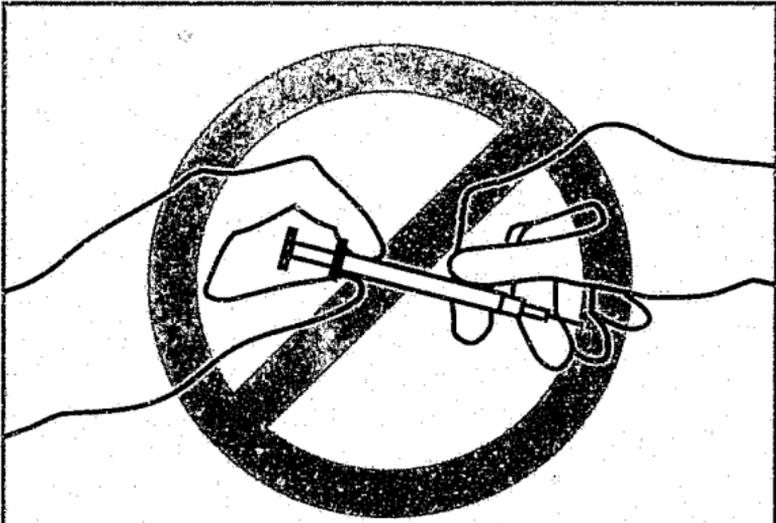
This booklet is a guide to understanding HIV and getting the right care as soon as you can. You can also share this booklet with family members and friends so they can learn more about HIV.

The booklet will tell you about some of the problems you will probably have to face and suggests questions you may want to ask your doctor, nurse, or other health care provider. Asking these questions will help you get the information you need to make decisions about your own health care.

## First Steps

Learn as much as you can about HIV. Finding out you have HIV infection can be frightening and confusing. Here are some questions you may want to ask your health care provider:

- What will HIV do to my health?
- Will I need to change the way I live?
- How will HIV affect my relationships with family, friends, sex partners, and people at work or school?
- What types of health care or other services will I need, now and in the future?



Sharing needles and syringes is risky.  
This is one way HIV infection is  
passed from one person to another.

Having HIV means that you can give HIV infection to someone else through unprotected (unsafe) sex or sharing needles or works if you inject drugs. Be sure to ask your health care provider how you can keep from spreading HIV.

### **Talking About Your HIV Status**

Your HIV status is very personal, and telling other people that you have HIV infection may be one of the hardest things you will ever have to do.

When you first find out you have the virus that causes AIDS, you may feel sad, depressed, ashamed, or afraid. Telling other people about your HIV infection may mean that you will get more support and help from others, but it can also lead to problems.

Local or state laws may require that your health care provider report your HIV status to the health department. Otherwise, your HIV infection should be kept confidential, unless you decide to talk about it. Ask your doctor about the laws in your state.

Your health care provider can help you decide whom to tell and help you tell them once you have decided to do so. Some of the people you may want to tell include:

- ❑ Sex partners
- ❑ Persons with whom you inject drugs
- ❑ Family
- ❑ Friends

You should talk with your sex partners about using condoms for safe sex and about the risks of having a baby with HIV. If you inject drugs, you will want to discuss the danger of sharing needles or works.

You may want to talk with members of your family about how your condition might affect them. You may also choose to tell your co-workers, neighbors or members of your church, and if you are a student, people at school, such as the school nurse, administrators, teachers, and classmates.

Some people with HIV choose not to talk about their health, and that's all right, too. It's your choice.



## Talking About Your HIV Infection

### Possible Benefits

- Support and help from family and friends
- In some states, better health and welfare benefits
- Greater chance that your sex partner or persons you have injected drugs with will get tested for HIV

### Possible Risks

- Rejection by partner, family, friends, school, club, or employer
- Changes in health benefits
- Trouble finding a place to live
- Loss of child custody

Although the risks of sharing information about your HIV infection with others may seem to outweigh the benefits, remember that these are only risks and might never happen.

## Taking Care of Yourself

If you have HIV infection, you may feel, look, and act just fine. But you need to take good care of yourself as soon as you find out you have HIV—this is the key to delaying the onset of more serious problems.

Try to keep a positive outlook. Hope is very important. Everyday there are new drugs and treatments for HIV that may help you. Each time you visit your doctor, be sure to ask about new treatments and clinical trials (research studies) in which you might take part.

Try not to worry. Worrying can lead to stress, and stress can weaken your immune system. Take steps to reduce stress. Activities that may relieve your stress include breathing exercises, leisure walks, reading, and community activities. Ask your health care provider about ways to cope with worry and stress.

See your doctor often. Don't wait until you get sick. The following hints may help you stay well longer:

- Get immunizations (shots) to prevent other infections.
- Avoid exposure to infection — for example, people with colds, other illnesses, and human or pet waste.
- Eat healthy foods. This will help keep you strong, keep your energy and weight up, and help your body protect itself.
- Exercise regularly to stay strong and fit.
- Get enough sleep and rest.
- Finish your medicines, even though you may feel better.

**Tell your health care provider right away if you have numbness, sores in your mouth, changes in your eyesight, or shortness of breath.**

## Monitoring Your Immune System

One of the blood cells infected by HIV is the CD4 cell (a special T cell). Its job is to defend your body from invaders such as viruses. The number of CD4 cells in your blood shows how strong your immune system is.

A test called the "CD4 cell count" is used to check on the progress of HIV infection. Your health care provider will probably ask you to have blood tests every few months so that your CD4 cell count can be used to show when to start medicines.

As long as your CD4 count is over 600, you will need to have it tested about every 6 months. If your CD4 count drops below 500, your doctor may suggest testing your blood more often and may start you on medicine to slow HIV.



## Starting Treatments

Your doctor should talk with you about the risks and benefits of starting treatment with drugs for HIV. AZT, now called ZDV (for zidovudine), is the most widely used drug for HIV. If ZDV does not work or causes side effects (for example, sleep problems, leg cramps, headaches, nausea, diarrhea, or anemia), your doctor may give you didanosine (ddI) or dideoxycytidine (ddC). Be sure to tell your doctor about any side effects you may have from ddI or ddC, such as belly pain or numbness in your hands or feet.

Remember, the treatments for HIV are changing rapidly, so be sure to ask your doctor if there are new treatments.

If your HIV infection worsens, you will be more likely to have other infections that take advantage of your weakened immune system. If your CD4 cell count falls below 200, or if you have had pneumonia or other symptoms, your doctor will probably recommend that you start taking trimethoprim-sulfamethoxazole or TMP-SMX (Bactrim®, Septra®, and generic products) to prevent the most common of these infections, *Pneumocystis carinii* pneumonia, or PCP. Most people have no problem with TMP-SMX, but if you develop a rash or severe stomach problems, stop taking the medicine and call your doctor right away to discuss other treatments.

HIV and HIV-related illnesses vary from person to person. Some people have been living with HIV for many years. Others become sick soon after their diagnosis. Your medical care plan will be designed especially for you and may differ somewhat from the care described in this booklet.

Here are some questions you should ask your doctor, nurse, or other health care provider:

- How often should my CD4 count be taken?
- At what CD4 count should I begin taking medicine for HIV infection?
- What about medicines to prevent other illnesses that can occur with HIV? How will these medicines help me? Do they have side effects?
- Are there new treatments?

## Detecting and Treating Other Diseases

### Tuberculosis

Because HIV weakens the body's ability to resist infections, you are at special risk for infection with the germ that causes tuberculosis (TB). Even if you become infected with this germ, proper treatment can keep it from turning into active TB. Be sure to ask your doctor, nurse, or other health care provider:

- How often should I be tested for TB infection? What kinds of tests are needed?
- How can I avoid becoming infected with TB?
- If I get TB, how can I avoid infecting others?

Tell your health care provider if you think you have been exposed to someone with TB.

If you become infected with the bacteria that causes TB, your doctor may give you the medicine, isoniazid (INH), which you will need to take once a day, every day, for a full year, even if you feel fine. Your doctor may also recommend that you take pyridoxine, a form of vitamin B<sub>6</sub>, each day to help reduce side effects from isoniazid. Be sure to tell your doctor about any side effects you may

have from the medicine, such as nausea, vomiting, loss of appetite, tiredness or weakness, skin rashes, or fever.

Instructions for taking medication for TB infection can be confusing. Work closely with your health care provider to be sure you complete your treatment.

## **Syphilis**

Syphilis is a sexually transmitted disease (STD). It often occurs with HIV infection but can be hard to recognize and treat in persons who have HIV. Untreated syphilis can cause severe nerve, heart, and blood vessel damage and even death.

You should tell your doctor about your full sexual and medical history. Some of the questions you may want to ask include:

- What are the tests for syphilis? How often should I be tested?
- How is syphilis treated?
- Will I need tests to make sure the treatment worked?
- How can I avoid passing syphilis to others?

Your doctor may give you blood tests to learn if you have syphilis and to see how far it has progressed. You also may need other tests. You should be tested for syphilis anytime you think you have been exposed to an STD.

If you have syphilis, you should tell your sex partners or persons who have injected drugs with you. Your health care provider or a health department worker can help you do this and tell you whether the law in your state requires that your sex partners be notified.

Penicillin shots are the usual treatment for early syphilis. For more advanced disease, you may require intravenous (IV) penicillin and perhaps a hospital stay. If you are allergic to penicillin, you may need to see a specialist.

## **Mouth and Eye Problems**

Mouth problems, such as candidiasis (thrush), and eye problems are some of the signs of HIV infection. Your health care provider should check your mouth and eyes at each visit. Be sure to:

- Tell your health care provider about changes in your eyes (blurry vision or infected eyes or eyelids) or mouth (sores, dryness, bleeding, difficulty swallowing, change in taste, pain, or loose teeth).
- Visit a dentist at least twice a year or more often if mouth problems develop.

Your doctor can treat most of your HIV-related mouth and eye problems. Sometimes you may also need to see a special dentist or an eye doctor.

## **Pap Tests for Women with HIV**

Pap tests help detect cancer of the cervix (mouth of the womb) at an early stage. Women with HIV are more likely to have abnormal Pap smears.

- If you are a woman with HIV, your health care provider should check you for STDs and perform a Pap test at least once a year.
- If you have ever had cancer of the cervix, venereal warts, or an abnormal Pap test, you should have checkups more often.

If your Pap test is abnormal, you may need to have a colposcopy. In this special type of examination, the doctor uses an instrument to get a close-up view of the cells and tissues of the vagina and cervix.

## Pregnancy and HIV

If you become pregnant and decide to have your baby, the most important thing you can do is get good prenatal care. The chances of passing HIV to your baby before or during birth are about one in four, or 25 percent, for each pregnancy.

As a general rule, treatment for HIV infection in pregnant women is the same as for others who are not pregnant. You should have a Pap test during your pregnancy, and your doctor will probably recommend a CD4 count as soon as prenatal care begins. Depending on the results, you may not need another CD4 count during your pregnancy.



If you become infected with the TB germ while you are pregnant, your doctor can give you medicine, and chest x-rays may be used with proper precautions.

If you are pregnant and have syphilis, you will need special care. Babies born to women with untreated syphilis can become seriously ill or die. Here are questions to ask if you are HIV-positive and pregnant:

- Should I be tested for syphilis during pregnancy?
- What treatments are used for syphilis during pregnancy? Are they safe for my baby?
- Will I be cured? Will my baby be cured?

Your immune system may work differently during pregnancy, so your doctor will watch you closely. Here are some questions you may want to ask:

- Will pregnancy affect my HIV infection?
- Will the medicines I take for HIV be safe for me and my baby?
- Will my baby get sick?
- Are there special HIV drug studies for pregnant women? If so, how can I take part in such a study?

After birth, your baby should be tested regularly for HIV infection, whether or not HIV is present at birth. The baby also should be tested for syphilis, even if you were treated during pregnancy. Because HIV infection can be passed through breast milk, you should not breastfeed your baby.

## Family Planning Decisions

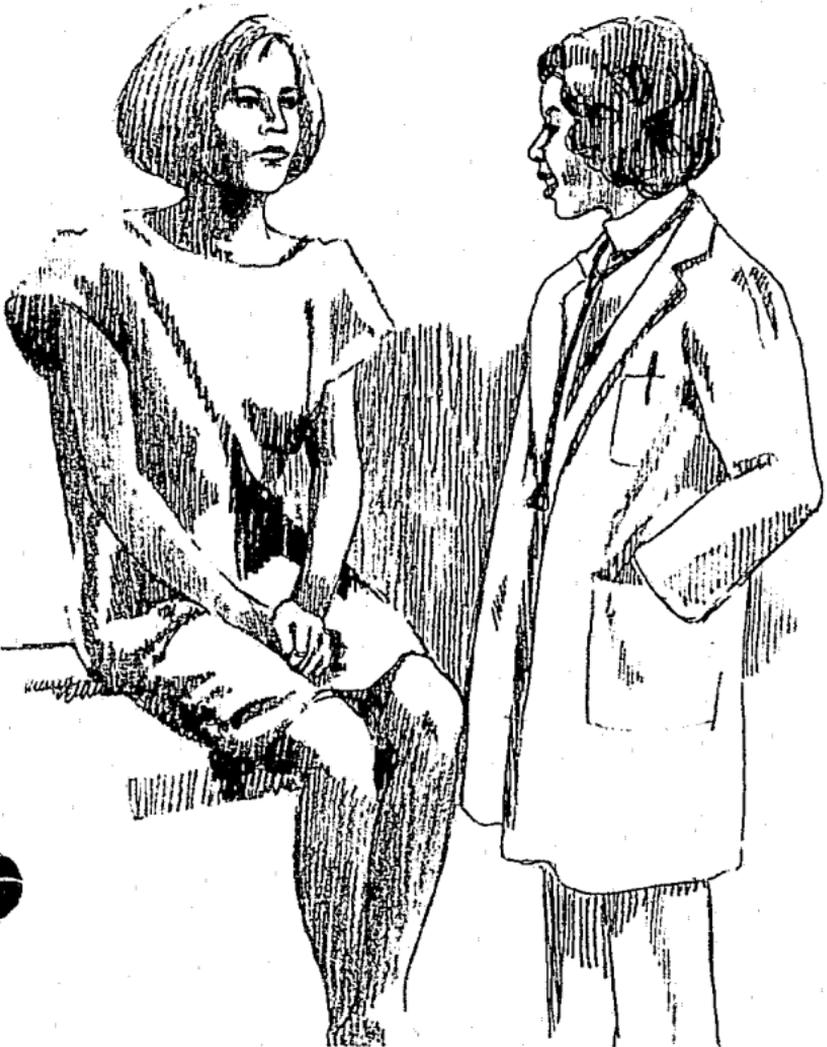
If you are thinking about avoiding pregnancy or becoming pregnant, you should talk with your health care provider about the issues that are important to you, such as:

- If I choose not to get pregnant, what birth control methods would be best for me?
- Will pregnancy make my HIV infection worse? How?
- Will HIV infection mean other problems for me during pregnancy or delivery?
- Will my HIV infection and the treatments I may need cause problems for my baby?

- If I am pregnant and choose not to continue the pregnancy, where can I go to terminate the pregnancy? What if I am refused help because I have HIV?
- If I choose to get pregnant, what community programs and support groups can help me and my baby?
- Once I become pregnant, should I use condoms anyway? If my partner also has HIV, do we still need condoms?

Remember, although HIV-related illnesses can be treated, as yet there is no cure for HIV. This means the infection, and likely AIDS as well, will be a part of your family's future.

If you are weakened by HIV, both you and your unborn baby will be at greater risk for other serious infections. Because you have HIV, both you and your baby will need care. You will need to plan for the care of your child if you get sick.



## Getting the Support You Need

A person or family living with HIV may need many kinds of support. Your health care provider and your local health and social services departments can help you find the support you need, including someone to:

- Answer your questions about HIV and AIDS.
- Help you find health care providers, get insurance, make health care decisions, and obtain food and housing.
- Provide transportation to and from health care appointments.
- Assist in planning ways to meet financial and daily needs.
- Refer you and your loved ones to support groups.
- Arrange for home nursing care or rehabilitation services.
- Represent you in legal matters.

Many people living with HIV feel better if they can talk with other people who also have HIV. Here are some ways to find others with HIV:

- Read HIV newsletters.
- Join support groups.
- Volunteer to help others.
- Be an HIV educator or public speaker, or write a newsletter.
- Attend social events to meet other people who have HIV.

## Additional Resources

There are many sources of information about living with HIV. Look in the telephone book for:

- Your local health department. They can tell you where to get tested for HIV and what services are available from public sources.
- Your local or state medical society to help you find a doctor.
- Your library. They may have many materials to help you learn about HIV and AIDS.

Some hospitals, churches, and the American Red Cross, as well as HIV and AIDS organizations, offer programs and sponsor support groups that may be listed in a special directory or your newspaper. Ask your librarian about newsletters and other printed materials.

Toll-free national hotlines and information clearinghouses can send you free publications and give you the latest news about drug-testing and clinical trials.

Here are some telephone numbers to help you get the information you need:

### General Information

#### National AIDS Hotline

English . . . . .(800) 342-AIDS (2437)

Spanish . . . . .(800) 344-SIDA (7432)

#### TDD Service for the Deaf

(800) 243-7889

#### National AIDS Clearinghouse

(800) 458-5231

### HIV/AIDS Treatment Information

#### American Foundation for AIDS Research

(800) 39AMFAR (392-6327)

#### AIDS Treatment Data Network

(212) 268-4196



## **For Further Information**

The information in this booklet was taken from the Clinical Practice Guideline on Evaluation and Management of Early HIV Infection. The guideline was written by a panel of private-sector experts sponsored by the Agency for Health Care Policy and Research. Other guidelines on common health problems also are being developed.

To order another copy of this booklet, call the National AIDS Hotline toll-free at **(800) 342-AIDS**, or write to:

**AHCPR HIV Guideline  
CDC National AIDS Clearinghouse  
P.O. Box 6003  
Rockville, MD 20849-6003**

To order copies of AHCPR-sponsored guidelines on other topics, call **(800) 358-9295** (for callers outside the U.S., only: (301) 495-3453) weekdays, 9 a.m. to 5 p.m., Eastern time, or write to:

**Agency for Health Care Policy and Research  
Publications Clearinghouse  
P.O. Box 8547  
Silver Spring, MD 20907**



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