

Health Reference Series

Seventh Edition

AIDS

SOURCEBOOK

Basic Consumer Health Information about the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS), Including Facts about Its Origins, Stages, Types, Transmission, Risk Factors, and Prevention, and Featuring Details about Diagnostic Testing, Antiretroviral Treatments, and Co-Occurring Infections, Such as Cytomegalovirus, Mycobacterium avium Complex, Pneumocystis carinii Pneumonia, and Toxoplasmosis

Along with Tips for Living with HIV/AIDS, Updated Statistics, Reports on Current Research Initiatives, a Glossary of Related Terms, and a List of Resources for Additional Help and Information



OMNIGRAPHICS

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Chapter 48

Coping with an HIV/AIDS Diagnosis

Finding out that you have human immunodeficiency virus (HIV) can be scary and overwhelming. If you feel overwhelmed, try to remember that you can get help and that these feelings will get better with time.

Testing positive for HIV is a serious matter but one that you can deal with. Starting HIV medications early is one of the best ways to take care of your health. This chapter will take you through the steps you need to take to protect your health:

- Understand your diagnosis
- Find support
- Work with your doctor
- Monitor your health
- Be aware of possible complications
- Protect others
- Start treatment
- Move forward with your life

This chapter includes text excerpted from “HIV/AIDS—Your Next Steps: Entire Lesson,” U.S. Department of Veterans Affairs (VA), February 8, 2018.

There are some things that you should know about HIV that may ease some of the stress or confusion you are feeling. Remember:

- **You are not alone.** Many people are living with HIV, even if you don't know that they are.
- **HIV does not equal death.** Having HIV does not mean that you are going to die of it. Most people with HIV live long and healthy lives if they get medical treatment and take care of themselves.
- **HIV does not mean acquired immunodeficiency syndrome (AIDS).** A diagnosis of HIV does not automatically mean that you have AIDS.
- **Don't freeze.** Learning how to live with HIV and getting into care and onto medications will help you to feel better and get on with your life. Your VA care provider can help you connect with a healthcare team that knows how to manage HIV.

Understand Your Diagnosis

When your medical provider tells you that you are HIV positive, it means that you have been infected with the HIV. However, the HIV test does not tell you if you have AIDS or how long you have been infected or how sick you might be. Soon after your diagnosis, your provider will run other tests to determine your overall health, and the condition of your immune system.

Learn about Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS)

The more you know about HIV and how to treat it, the less confused and anxious you will be about your diagnosis. The more you learn, the better you will be at making decisions about your health. You don't have to learn it all at once, however, it is important to go at a pace you are comfortable with. This may be fast, slow, or in-between. You may want to go over the same information several times.

There are many ways to learn about HIV and AIDS:

- **Read information online.** Remember that there is a lot of Internet information that can be inaccurate or misleading—be sure to look for reputable sites whose content can be trusted. Check out government or nonprofit educational organizations that deal with HIV and AIDS issues.

- **Use your local library.** The most updated information will be in the library's collection of newspapers and magazines (books about HIV and AIDS may be out of date by the time they are published).
- **Check for on-site library in local medical center.** Check with your local medical center to see if there's an on-site library where you can find patient materials on HIV and AIDS.

Find Support

Talk with others who have been diagnosed with HIV and AIDS. Ask your healthcare provider if they know of any support groups. Or you can go online, where you can find message boards and chat rooms. Always discuss what you learn from these sources with your provider. The information may not be accurate; and even if it is, it may not be right for your particular situation.

Finding support means finding people who are willing to help you through the emotional and physical issues you are facing. If you let the right people in your life know that you are HIV positive, they can:

- offer you support and understanding
- provide you with assistance, such as helping with child care, doctor visits, and work
- learn from you how HIV is spread and work with you to prevent the virus from spreading

Telling Others

Deciding to tell others that you are HIV positive is an important personal choice. It can make a big difference in how you cope with the disease. It can also affect your relationships with people.

If you decide to share information about your diagnosis, it is best to tell people you trust or people who are directly affected. These include:

- family members
- people you spend a lot of time with, such as good friends
- all your healthcare providers, such as doctors, nurses, and dentists
- sex partner(s)

You don't have to tell everyone about your HIV status right away. You might want to talk with a counselor or social worker first.

Join a Support Group

Some medical centers have support groups for veterans with HIV, so you may want to ask your provider if your center has one that you can join for support and for more information about living with HIV. Joining a group of people who are facing the same challenges you are facing can have important benefits. These include:

- feeling better about yourself
- finding or strengthening your life focus
- making new friendships
- improving your mood
- better understanding your needs and those of your family

People in support groups often help each other deal with common experiences associated with being HIV positive. Support groups are especially helpful if you live alone or don't have family and friends nearby. There are different types of support groups, from hotlines to face-to-face encounter groups. Here are descriptions of some of the most popular types, and suggestions about how to find them.

Hotlines

Hotlines can provide information, support, or link you with local services. Find a hotline in your area by talking to a social worker in your hospital. Or look in the telephone book, in the yellow pages under "Social Service Organizations."

Professional Help

You can get referrals to mental health professionals, such as psychologists, nurse therapists, clinical social workers, or psychiatrists. You also will likely have a social worker who is part of the HIV clinic team where you will receive care. You can also get help for substance use.

Self-Help Organizations

Self-help groups enable people to share experiences and pool their knowledge to help each other and themselves. They are run by members, not by professionals (though professionals are involved). You may, for example, be able to find groups specifically for women, African

Americans, gay men, transgender individuals, or other specific groups of people. Because members face similar challenges, they may feel an instant sense of community. These groups are volunteer, nonprofit organizations, with no fees (though sometimes there are small dues).

Work with Your Provider

HIV is the virus that causes AIDS. If ignored, it can lead to illness and death. This is why it is so important to get medical care and start treatment if you find out you have HIV. Please see a doctor or nurse practitioner with experience in treating people with HIV—he or she can help you to stay well. Most VA clinicians who treat HIV are specialists in infectious disease. They work with a team of other health professionals who focus on HIV as a chronic, or lifelong, disease.

Treatments for HIV are not perfect (no medicine is), but are very tolerable and extremely effective for most people. They also work very well to minimize the chance that you may transmit HIV to sex partners (for pregnant women they also decrease the risk of infecting the baby). A doctor or other healthcare provider can explain the best options for you. If you work with your healthcare provider in planning your care, you can deal with the disease in a way that is best for you.

Before Appointments

Start with a list or notebook. Prepare for your appointment with your doctor by writing down:

1. any questions that you have (print out questions to ask your doctor and take it to your appointment)
2. any symptoms or problems you want to tell the doctor about (include symptoms such as poor sleep, trouble concentrating, feeling tired)
3. a list of the medications that you are taking (include herbs and vitamins), including a list of any HIV medications you have taken in the past and any HIV-related problems you have had when taking them
4. upcoming tests or new information you've heard about
5. changes in your living situation, such as a job change

That way you won't forget anything during the appointment. You may want to ask a friend or family member to come with you and take

notes. It can be difficult for you to take notes and pay attention to what your doctor is saying at the same time.

During Appointments

Go over your lab results, and keep track of them. If your health-care provider wants you to have some medical tests, make sure you understand what the test is for and what your provider will do with the results. If you don't understand what your medical provider is saying, ask him/her to explain it in everyday terms. If you feel your provider has forgotten something during the appointment, it is better to ask about it than to leave wondering whether something was supposed to happen that didn't. It's your right to ask questions of your provider. You also have a legal right to see your medical records. After all, it's your body. Be honest. Your provider isn't there to judge you, but to make decisions based on your particular circumstances. Tell your doctor about your sexual or drug use history. These behaviors can put you at risk of getting other sexually transmitted diseases as well as hepatitis. If your body is fighting off these other diseases, it will not be able to fight off HIV as effectively. You may get sicker, faster. If you have sex with someone of the same sex or someone other than your spouse, it's OK to tell your medical provider.

Monitor Your Health

Once you have been diagnosed with HIV, you need to pay closer attention to your health than you did before. You can keep track of your immune system in two ways:

1. Have regular lab tests done. Lab tests often can show signs of illness before you have any noticeable symptoms.
2. Listen to what your body is telling you, and be on the alert for signs that something isn't right. Note any change in your health—good or bad. And don't be afraid to call a doctor.

Have Regular Lab Tests

Your medical provider will use laboratory tests to check your health. Some of these tests will be done soon after you learn you are HIV positive.

The lab tests look at several things:

- how well your immune system is functioning

- how well your medications are controlling the HIV (or, if you are not taking HIV medications, how rapidly HIV is progressing)
- certain basic body functions (tests look at your kidneys, liver, cholesterol, and blood cells)
- whether you have other diseases that are associated with HIV

For your first few doctor visits, be prepared to have a lot of blood drawn. Don't worry. You are not going to have so much blood drawn at every appointment.

Be Aware of Possible Complications

By weakening your immune system, HIV can leave you vulnerable to certain cancers and infections. These infections are called "opportunistic" because they take the opportunity to attack you when your immune system is weak. HIV also is an inflammatory disease that affects many parts of the body, not just the immune system. That means that HIV can affect organs like the brain, kidneys, liver, and heart and may increase the risk of some cancers. HIV medicines can sometimes have side effects. Sometimes these can raise the risk of heart disease or kidney disease. It is important that you let your medical providers know if you notice any concerning symptoms.

Know When to Call a Medical Provider

You don't need to panic every time you have a headache or get a runny nose. But if a symptom is concerning you or is not going away, it is always best to have a provider check it out even if it doesn't feel like a big deal. The earlier you see a provider when you have unusual symptoms, the better off you are likely to be.

The following symptoms may or may not be serious, but don't wait until your next appointment before calling a doctor if you are experiencing them.

Breathing problems:

- persistent cough
- wheezing or noisy breathing
- sharp pain when breathing
- difficulty catching your breath

Skin problems:

- Appearance of brownish, purple or pink blotches on the skin
- New or worsening rash—especially important if you are taking medication

Eye or vision problems:

- blurring, wavy lines, sudden blind spots
- eye pain
- sensitivity to light

Aches and pains:

- numbness, tingling, or pain in hands and feet
- headache, especially when accompanied by a fever
- stiffness in neck
- severe or persistent cough
- persistent cramps
- pain in lower abdomen, often during sex (women in particular)

Other symptoms:

- mental changes—confusion, disorientation, loss of memory or balance
- appearance of swollen lymph nodes (glands), especially when larger on one side of the body
- diarrhea—when severe, accompanied by fever, or lasting more than 3 days
- weight loss
- high or persistent fever
- fatigue
- frequent urination

Protect Others

Once you have HIV, it is important that you take measures so you don't pass the virus to sex partners, to injecting drug partners, or (for women who wish to become pregnant) to a baby during pregnancy

or delivery, or by breast-feeding. Starting and staying on HIV medications (antiretroviral therapy, or ART) is a hugely effective way to minimize the risk of transmitting the HIV virus. Using condoms and clean injection equipment also can prevent HIV from passing to other people and condoms can also protect you from getting other sexually transmitted diseases. Partners who do not have HIV also can use PrEP (preexposure prophylaxis), a daily pill that can prevent HIV infection.

Sometimes it can be difficult to explain that you have HIV to people you have had sex with or shared syringes with in the past. However, it is important that they know so they can get tested. If you need help telling people that you may have exposed them to HIV, many city or county health departments will tell them for you, without using your name. Ask your provider about this service.

Before telling your partner that you have HIV, take some time alone to think about how you want to bring up the subject.

- Decide when and where would be the best time and place to have a conversation. Choose a time when you expect that you will both be comfortable, rested, and as relaxed as possible.
- Think about how your partner may react to stressful situations. If there is a history of violence in your relationship, consider your safety first and plan the situation with a case manager or counselor.

Consider Treatment

When or whether to start treatment for HIV is a decision that each person must make with his or her providers. In general, experts recommend starting HIV treatment very soon after your diagnosis; this can help prevent some of the damage that HIV causes in many parts of the body. HIV treatment (ART) is strongly recommended for all HIV-infected people, and more urgently for anyone who has evidence of immune suppression (a cluster of differentiation 4+ (CD4+) cell count that is below normal) or an AIDS diagnosis (an infection or cancer associated with HIV). It also is more urgently recommended for anyone who has a sex partner who is not infected with HIV, and for women who may become pregnant.

Move Forward with Your Life

Life does not end with a diagnosis of HIV. In fact, with proper treatment, people with HIV usually live long healthy lives. HIV can be

a manageable chronic disease, like diabetes or heart disease. Taking care of your overall health can help you deal with HIV:

- Take your medicines every day
- Get regular medical and dental checkups
- Eat a healthy diet
- Exercise regularly
- Avoid smoking and recreational drug use
- Go easy on alcohol
- Use condoms during sex (it can protect others from getting HIV, prevent unintended pregnancy, and protect you from other sexually transmitted diseases)