

Chapter 36

Coping with an HIV/AIDS Diagnosis

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Your next steps

Finding out that you have 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. 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

Text in this chapter is excerpted from “Getting an HIV Diagnosis – Your Next Steps: Entire Lesson,” U.S. Department of Veterans Affairs (VA), September 27, 2015.

- Consider treatment
- Move forward with your life

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 can live long healthy lives if they get medical treatment and take care of themselves.
- A diagnosis of HIV does not automatically mean that you have AIDS.
- Don't freeze: Learning how to live with HIV and getting in touch with a health care team that knows how to manage HIV will help you to feel better and get on with your life.

Understand your diagnosis

When your medical provider tells you that you are HIV positive, it means that you have been infected with the Human Immunodeficiency Virus (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 HIV and 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

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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 current information will be in the library's collection of newspapers and magazines.
- 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 doctors 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 going to face. 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 running errands and 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; and
- all your health care providers, such as doctors, nurses, and dentists.

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 VA Medical Centers have a support group 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 a new life focus, making new friendships, improving your mood, and 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

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." Ask the hotline to "match" you with another person with a history like yours. He or she can give you practical advice and emotional support over the telephone.

Professional help

Veterans with HIV 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 where you will receive care. You can also get help for drug abuse.

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). Because

members face similar challenges, they 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 if you find out you have HIV. Do not be afraid to seek a doctor or nurse practitioner with experience in treating HIV-infected patients—he or she can help you to stay well. Most doctors 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 effective for most people. They also work very well to decrease the chance that you will transmit HIV to sex partners (for pregnant women they also decrease the risk of infecting the baby). A doctor or other health care provider can explain the best options for you.

If you work with your health care 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:

- any questions that you have
- any symptoms or problems you want to tell the doctor about (include symptoms such as poor sleep, trouble concentrating, feeling tired)
- 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.
- upcoming tests or new information you've heard about
- 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 work, and keep track of your results. If your doctor wants you to have some medical tests, make sure you understand what the test is for and what your doctor will do with the results. If you don't understand what your doctor is saying, ask the doctor to explain it in everyday terms.

If you feel your doctor 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 doctor. You also have a legal right to see your medical records. After all, it's your body.

Be honest. Your doctor 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 doctor. You cannot get kicked out of the medical center or lose your benefits if you have sex with someone of your same sex, or someone other than your spouse.

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. First, have regular lab tests done. Lab tests often can show signs of illness before you have any noticeable symptoms.

Second, 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 doctor 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 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.

In addition, HIV is recognized to be 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.

Certain changes can happen to HIV-positive people who are living longer and taking HIV medicines. Some people who were treated with older HIV medicines have experienced visible changes in body shape and appearance. Sometimes these changes can raise the risk of heart disease and diabetes.

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.

Protect others

Once you have HIV, you can give the virus to others by having unprotected sex or by sharing needles (or, if you are pregnant and not on HIV medications, you can pass HIV to the baby during pregnancy, delivery or by breast-feeding). This is true even if you are feeling

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
- Onset of 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, 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

perfectly fine. Using condoms and clean needles can prevent infecting other people. It can also protect you from getting other sexually transmitted diseases. Taking HIV medications that suppress HIV also greatly reduces the likelihood of transmitting HIV infection to another person.

Sometimes it can be difficult to explain that you have HIV to people you have had sex with or shared needles with in the past. However, it is important that they know so that they can decide whether to 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

Whether or not to start treatment for HIV is a decision that each person must make with his or her providers. HIV medication (known as antiretrovirals) is recommended for all HIV infected people, and more urgently for anyone who has evidence of immune suppression (a CD4+ cell count of less than 350–500) 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. Current guidelines recommend starting HIV treatment because HIV is known to affect many parts of the body even early on in infection, and some damage caused by HIV can be irreversible.

In general, you and your provider will need to consider:

- how healthy your immune system is (this is usually measured by your CD4 count)

- whether or not you have AIDS
- whether you can stick to a treatment plan
- what your other medical problems are
- whether you have sex partners who may be at risk of becoming infected
- if you are a woman, whether you plan to become pregnant

Move forward with your life

Life does not end with a diagnosis of HIV. In fact, with proper treatment, people with HIV can 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:

- 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, and can protect you from other sexually transmitted diseases)