

# **NOW THAT YOU KNOW: A Guide to Living with HIV**

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# **NOW THAT YOU KNOW: A Guide to Living with HIV**

We know that learning you are HIV positive can stir up many different feelings. Most of us felt angry, confused, and scared, but new medications and approaches to treating HIV have given us a new sense of hope. Now that you know, you may be thinking about what to do first and who to tell. You will be learning lots of important information including new medical terms, possible treatment options, and making new decisions. As a result, you may start to feel overwhelmed. But remember, you don't have to figure it all out today, and you don't have to do it alone.

This guide will help you through the first steps to living healthy with HIV, including:

- The importance of a strong support network
- Available support services
- What to look for in a doctor
- What to expect when getting into medical care
- Living safe and healthy with HIV

Some of the information in this guide may be useful today and some you may refer to as you begin making decisions about your health.

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# Accessing Support Services

There is no one way to address the emotional and physical impact of living with HIV. Some people get encouragement and support from family and friends. Others find it helpful to talk to another person living with HIV. Support groups for people living with HIV can provide a safe place to meet and connect with others living with HIV.

There are several HIV peer programs in Massachusetts that can connect you with someone in your area to talk to. There are also drop-in centers that offer a range of services including group meals, support groups, counseling, and social activities. There are prevention programs for people with HIV that can help you deal with being HIV positive and show you how to live a safe and healthy life.

**To find out what is available in your area call the AIDS Action Committee Hotline at 1-800-235-2331, (TTY 617-437-1672) or go to [www.aac.org](http://www.aac.org).**

Friends and family can also be a good source of support, but it can be hard to know how to tell people. There are some tips for how and when to disclose your status on page 14 of this guide.

***Whether you decide to tell your family and friends, or work with an agency, it's important to have a strong support network of people you trust.***

There are people and places you can go to get the support and services you might need. HIV case managers are trained to identify what resources are available and work with you to determine which services you may need.

***Your case manager can answer questions, help you find a doctor, and locate important services such as:***

- Free or low-cost medical care
- Assistance with paying for medications
- Health insurance assistance
- Medication adherence programs
- Transportation and child care for doctor's visits
- Support groups
- Mental health and other counseling services
- Prevention programs for people living with HIV
- Food assistance
- Substance abuse treatment programs
- Needle exchange programs
- STD screening and treatment
- Hepatitis screening and vaccination

To find a case manager and identify resources available in your area, call the AIDS Action Committee Hotline at 1-800-235-2331, (TTY 617-437-1672) or go to [www.aac.org](http://www.aac.org).

## Finding an HIV Doctor

Medical care for HIV can be complicated. That's why one of the most important things you can do is choose a doctor with experience in the treatment of HIV. Research shows that health care providers with more HIV experience provide better HIV care. So, if your current doctor is not an experienced provider of HIV care, he or she should consult regularly with an HIV expert or refer you to an HIV specialist.

***Make sure you and your doctor have similar approaches to health care. You want a doctor who will listen, explain your options, answer your questions, and make decisions WITH YOU, NOT FOR YOU.***

You want a doctor you can trust and talk to about your life, including any sexual and drug use activities. If you aren't able to be open about your life, you might not be getting the best and most personalized care. *The more your doctor knows about you the better care he or she can provide you.*

## Your First Doctor's Visit

During your first visit, your doctor will want to do a general assessment of your overall health. Behaviors that put you at risk for HIV also put you at risk for other sexually transmitted diseases (STDs) and hepatitis. In order to determine if you need other services or screening for STDs, hepatitis or substance abuse, ***your doctor should know about your sexual and drug use history. This is important information because if you are fighting multiple infections or conditions, your body will not be able to fight the HIV as well and you may get sicker, faster.*** So get checked regularly since hepatitis symptoms may not show up for many years, and not all STDs have symptoms.

Information you share with your doctor is confidential and is protected by state and federal privacy laws. If you have questions about the confidentiality of your information, ask your doctor.

To find out more call the Division of STD Prevention at 1-866-749-7122 or go to [www.mass.gov/dph/cdc/std/divstd.htm](http://www.mass.gov/dph/cdc/std/divstd.htm).

# Monitoring HIV

To get a first look at how you are doing, your doctor will want to do several tests. The two most common tests used to monitor HIV and determine whether or not you should begin taking HIV drugs are the T-cell and viral load tests.

***The T-cell test counts infection-fighting white blood cells called T-cells or CD4 cells. A falling T-cell count can be a sign that HIV is damaging your immune system. The viral load test measures the amount of HIV in your blood and how quickly it is multiplying.***

To get the most accurate results, your doctor will do these tests two or three weeks apart. This is called baseline testing. After your baseline is established, your doctor will probably do these tests every three months to continue monitoring your health. When you get your blood work results, your doctor will explain them to you, and together, you will consider your treatment options.

## Choosing a Treatment Plan

Deciding whether or not to start treatment is based on several factors, including blood work results and your readiness to start taking medications. Before deciding on your treatment plan make sure you understand how the drugs work and why you need to take them. Talk to other people with HIV about what drugs they are taking and how they manage taking them, read about the treatment being recommended to you by your doctor, and go to HIV websites. Be sure your doctor knows how you feel about using medications and about other treatments you are using or want to try, including non-medical treatments like vitamins and herbs.

Many HIV medications can cause side effects. Knowing what side effects you are willing to tolerate may be an important factor in considering if you are going to start taking medications or which medications you and your doctor choose. The most common side effects include nausea, diarrhea, and headaches. There are other side effects that may impact your long-term health. Ask your doctor to explain all the possible side effects of the drugs you are taking and ways that can help you manage them.

Some individuals have a form of HIV that is resistant to certain HIV drugs. This means that the drugs will not work against the virus. Others may become resistant to certain drugs because the drugs were not taken correctly or are no longer working. In order to determine what treatment plan is right for you, your doctor may want to do a drug resistance test to see if your virus is resistant to any HIV drugs. Fortunately, there are more treatment options available for people living with HIV than ever before.

***While HIV drugs are far from perfect, we know people can live longer and healthier by choosing the right treatment plan and sticking with it.***

**Here are some considerations when deciding on a treatment plan:**

- Most of the HIV drugs can be taken twice a day and others three times – are you able to take drugs three times a day?
- Some drugs need to be refrigerated. Do you live and/or work in a place that has a refrigerator?
- Some drugs need to be taken with food and others on an empty stomach. Is your eating schedule flexible?
- Can you put up with the drug's side effects?

**Here are some questions to ask once you and your doctor have chosen a treatment plan:**

- How much should I take?
- What times should I take it?
- Should this be taken with or without food?
- Can this drug react with other drugs or anything else I may be taking?
- What are the possible side effects?
- What are the possible long-term side effects?

## **Understanding Treatment Adherence**

Once you have started taking your HIV drugs, it is important that you take each drug as prescribed by your doctor: every dose, every day and according to instructions. This is called treatment adherence. If you don't take your medication as prescribed, you may become resistant to the medication.

This could limit your future treatment options.

Side effects may be the biggest reason why some people stop taking their drugs. If you are having side effects or a hard time sticking to your treatment plan, be sure to talk to your doctor. You and your doctor can talk about other HIV treatment options that might work better for you.

***It's important not to change or stop your medications without talking to your doctor.***

**Here are some tips on how to stick to your treatment plan:**

- Make a list of what drugs you take, when you need to take them, and check it everyday.
- Ask about things that can help, like pillboxes, timers, or support groups.
- Ask people you trust to help you remember to take your medication.
- Ask your doctor what you should do if you forget or miss a dose of your medication.

# Understanding Hepatitis & HIV

The three most common types of hepatitis, or inflammation of the liver, caused by viruses, are hepatitis A, B and C. There are vaccines for hepatitis A and B, but not C. Check with your doctor about being screened and vaccinated.

Some people have both hepatitis C (Hep C) and HIV. Like HIV, people get Hep C through contact with blood. Hep C is easily spread when people who use drugs share works, including needles, cotton, and cookers. Although Hep C can also be passed through sex, this is uncommon. There is no vaccine for Hep C, but there are things you can do to keep your liver healthy and available treatments that can be effective. For people with HIV, Hep C may cause liver damage more quickly. This damage to the liver could make it more difficult to take anti-HIV medication. Treating both HIV and Hep C is complicated, so if you think you might have hepatitis, be sure to tell your doctor.

**To find out more about hepatitis, call the Hepatitis Hotline at 1-888-443-HEPC (4372) or go to [www.masshepc.org](http://www.masshepc.org).**

## Telling Others

As you begin building your support network, you will need to consider who you are going to tell. This decision can be hard. ***You don't have to tell everybody. Take your time to decide who to tell and how you will approach them. Be sure you're ready.***

**Here are some things to consider when deciding who to tell:**

- **Know why** you want to tell them.  
What do you want or need from them?
- **Anticipate** their reaction. What's the best reaction you could hope for? The worst you might have to deal with?
- **Prepare** yourself. Get informed about your health.  
You may want to have information ready to give the people you tell like a pamphlet or hotline number.
- **Get support.** Talk it over with someone you trust or others who are HIV positive and come up with a plan.
- **Encourage** any sexual or drug-sharing partners to get tested. You can tell them yourself or have someone from the health department tell them without saying anything about you.
- **Accept** the reaction. You can't control how others will deal with your news.

# Staying Healthy and Keeping Your Partner Safe

HIV does not spread easily from person to person. HIV is found in blood, semen (cum), vaginal fluid or breast milk. In order to pass or get HIV, it has to get into your body or your partner's body. HIV can also be passed from mother to child during pregnancy, delivery and through breast-feeding. But there are ways to make sure you and your sex and/or drug using partners stay safe.

***Lowering your risk of passing HIV to others may mean changing the way you have sex or use drugs.*** This can be hard, but you should be sure your partners do not come in contact with your blood or sexual fluids.

## **To lower your risk of passing HIV to others:**

- Talk with your partners about being HIV positive.
- Ask your partners about their health.
- Decide with your partners what you are willing to do to stay safer.
- Use condoms during anal or vaginal sex.
- Do not share needles or works, including cotton, cooker or water.

## **For women who are pregnant or considering pregnancy:**

Getting treatment at any point in your pregnancy will give you a better chance of having a healthy baby, so:

- Ask your doctor about new treatments.
- Talk with your doctor about ways to keep you and your baby healthy during pregnancy and after giving birth.
- Continue your prenatal care throughout your pregnancy.

# NOW THAT YOU KNOW

Now that you know, you can be in control. What you want out of life doesn't have to change because you have HIV. Take steps toward living a safe, full and healthy life. The next step is yours. We hope this guide has given you the information and resources you need to find a doctor, to tell a friend or family member, to think about treatment options, to keep you and your partners safe, and to find the support you need. Living with HIV can be complicated, but you are in control.

**For additional information & resources, call 1-800-235 2331.**

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