

Day One: After you've tested positive

A positive HIV antibody test is scary news, but you have time to consider the many aspects to this new development in your life. As we learn more about HIV and as better therapies are developed, it's entirely possible to live a long life with HIV after testing positive. The key is getting into health care and using suitable therapies.

Your diagnosis is a wake-up call to be more proactive with your health, and it's better that it happened now rather than later. If you had waited for HIV disease to appear, some of your best medical options would already be lost.

Given the right attitude and information, most people can live a healthful life with HIV. And although services are out there, like medical help, support groups or referrals to housing or food resources, it's up to you to engage with them and decide how well they suit your life. Sometimes you'll have to keep working at it because the first place or first doctor may not be the right fit, or you may want more resources.

This publication can help you with the things you need to do:

- › learn more about HIV and how it can affect you;
- › understand the tests you'll use; and
- › find ways to promote and maintain your health.

What is HIV disease?

Simply put, HIV disease is a disease of the immune system, although it can infect most every type of cell in the body like brain or nerve cells. HIV (*human immunodeficiency virus*) causes disease because, after it gets into immune cells, it uses them to reproduce over and over.

This constant replication throughout the body causes HIV disease, as infected cells function poorly or die prematurely. Over time, your body can lose its ability to fight off other illnesses, which are called *opportunistic infections*, or OIs.

This gradual damage to the immune system doesn't happen the same way in everyone, or even at the same pace. In some, it may not happen at all. In a small percentage of people, HIV can destroy their immune systems in just a few years. But many others remain well for many years. On average, without using HIV therapy, most people remain well for about 10 years before facing their first serious symptoms.



Even though you probably feel well, it's still considered *HIV disease*. The word *disease* makes it seem like you should feel sick, when in fact you can feel quite well a lot of the time. Some people don't think of it that way; instead they say they *live with HIV* or are *HIV-positive*. It's really the same thing.

However, the term *AIDS* is different. In this case, a person with AIDS not only has HIV but also has certain conditions. These include a CD4 count below 200, a CD4 percentage below 14%, and/or one of the illnesses found on the CDC's list of AIDS-defining conditions. AIDS can develop after living many years with HIV.

HIV itself can differ from person to person, and treating it can also differ. What works for someone else may not be what works best for you, so it may take some time to figure that out. Although there are well-studied guidelines in place to treat HIV, many things can impact this, such as your lifestyle, pregnancy, your willingness to take meds, your ability to get

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to doctor appointments, and other conditions like diabetes or hepatitis, among others.

In the end, HIV disease can be treated with minimal impact on a person's life in many cases. We know much more today about how to treat HIV and it's getting better and easier with each passing year. It's very possible that you can live a healthful life with HIV.

Disease progression

HIV is a "spectrum" illness, meaning there are different stages to it. HIV disease can progress slowly or quickly. Several studies have researched the rate at which it progresses when left untreated. Most conclude that if their HIV is *left untreated*, about 1 in 2 people progress to AIDS within about 10 years of infection. About 3 in 4 reach AIDS by the 15th year.

Children born with HIV and people infected through blood transfusion seem to get sick more quickly. Studies suggest that when women have access to and seek regular care and monitoring, their progression rates are similar to and perhaps even slower than men. Studies that include people with hemophilia are inconclusive about their rates of progression.

Why people progress at different rates is uncertain. It may be due to the strain of HIV a person gets. Others believe it's influenced by genetic differences in people, while others suspect that lifestyle factors make a difference.

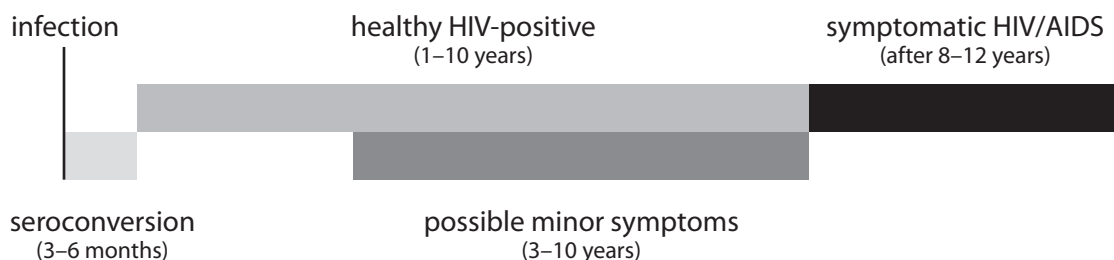
For long periods, often several years, the body copes effectively with HIV in many people. Most people feel normal and suffer no obvious ill effects. Despite this, most researchers believe that damage is still being done to the immune system. Many scien-

tists believe that starting treatment at this time may have the greatest impact, though others remain skeptical.

However, without treatment, the body will slowly lose its ability to fight infections. Some infections, like *Pneumocystis jiroveci* pneumonia (PCP), become likely when CD4 counts fall below 300 or 200. Minor infections can occur at counts above 300. Other life-threatening infections are more likely when the count falls below 100 or 50.

Some people say they hesitate to act on their health before they're sick because today's treatments are not perfect, hoping to wait for something better to come along. However, no one knows when "perfect" treatments will become available. It's well proven that today's treatments can extend a person's life. Although we can't predict the results for everyone, we do know what happens without treatment.

HIV disease over time without therapy



This graphic represents *average* times; so times may vary greatly from person to person.

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Two common blood tests and what they tell you

Your doctor will regularly run blood tests, about every 3 months, to keep track of how your general health is as well as to keep an eye on your HIV. Although there's a long list of possible tests that s/he may run, we describe here 2 of the more common ones. Both are important and should be considered together when making treatment decisions.

No single test result gives a total picture of immune health or disease progression, but taken together over time CD4 counts and viral load tests help guide you and your doctor about what treatments to use, when and when not to use them, and how well they're working. For more information, read Project Inform's publications, *Blood Work: Two Common Tests to Use* or *Blood Work: A Useful Tool for Monitoring HIV*.

CD4 count tests

By itself, a CD4 count doesn't tell you enough about the state of your HIV nor does it tell you how they're functioning. The count only shows that the level of CD4 cells is below normal (as compared to an HIV-negative person), to varying degrees. However, different ranges of CD4s point to making certain treatment decisions. These are explained below. Also, read the Federal Guidelines box on page 4.

ABOVE 500: CD4 counts above 500 generally suggest no immediate danger. While an occasional drop to 500 may be normal, a steady or falling count over time towards 500 or even 600 is not normal and suggests a weakening immune system. Minor HIV-related infections are rare. People can start therapy above this level.

350-500: CD4 counts in this range indicate noticeable decline of the immune system although serious symptoms are uncommon. If your viral load tests indicate significant viral activity, you may want to consider therapy. All people should be on therapy, though some may choose not to.

200-350: All people should be on therapy. While some people have symptoms of illness before major infections occur, this is not always the case. A person may remain stable for many years, especially with thoughtful health care. Some progress directly from apparently good health to serious OIs.

BELOW 200: CD4 counts in this range constitute an AIDS diagnosis, and all people should be on therapy. Most people are at greatest risk for infections, and some therapies are necessary to prevent severe illnesses such as PCP, CMV or MAC.



FACING NEW DECISIONS? WONDERING WHAT'S THE NEXT STEP?

HIV Health InfoLine: 1-800-822-7422 (toll-free)
10a-4p, Monday-Friday, Pacific Time

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Federal Guidelines

The Federal Guidelines were updated January 1, 2011. They recommend everyone to start therapy who has a CD4 count below 350 or has had an AIDS-defining illness. Therapy should also be started — regardless of CD4 count — in pregnant women, people with HIV-related kidney disease, and people living with hepatitis B disease where treatment is warranted. As for people with CD4s between 350–500, half the members of the Guidelines panel *strongly* recommends starting while the other half *moderately* recommends this. For people with CD4s above 500, half the panel favors starting while the other half considers this optional for the patient.

Viral load tests

Tests are available that directly measure the amount of new HIV being produced and released in your blood. These are called *viral load* or *PCR tests*. They're also used to measure the effects of therapy and the risk of disease progression.

In general, viral load should be kept as low as possible for as long as possible, preferably *undetectable* or *below the limit of detection*. This means below 50 copies, which is the limit that most tests can detect down to and which is also what results in the best possible medical outcomes. If you're undetectable, that means your immune system and the meds you're taking are keeping HIV under control. However, this *doesn't* mean that HIV is no

longer there. It's present, but just not in amounts that a viral load test can detect. Higher levels — ranging from about 30,000 (in women) to 60,000 (in men) to upwards of millions of copies of virus — are linked to faster disease progression.

When to start treatment

Getting the earliest possible treatment is generally recommended for treating illnesses. Biologically, there's little reason to think that HIV is any different. In fact, early treatment may be even more important because of the seriousness of the disease. But just what "early" means in the case of HIV disease is not so clear.

When to start HIV meds is the subject of great debate and theory. On the one hand the question of when

to start can be a matter of personal choice. But on the other, a great deal of medical evidence clearly points to some guidelines on when to start.

Some people believe that starting treatment is wise immediately upon knowing your diagnosis, whether or not your CD4 count is falling, viral load is high or rising, or whether symptoms are present. Waiting might let HIV progress faster. So, starting earlier may prevent losing critical cells in your immune system.

However, some doctors prefer to start treatment until later in the disease. They believe it's best to save the drugs for later when HIV is more active or when your immune system shows obvious damage. They fear that treating too early may "use up" the medicines before they're most needed. They also fear that people will have long-term side effects from the drugs before they're most needed. This makes sense since none of the current drugs can be used indefinitely. Almost all researchers agree that it's necessary to start HIV meds when symptoms are present, your CD4 count is falling, or your viral load is high.

For more information on HIV treatment strategies, read Project Inform's publications, *Making Decisions about Therapy* and *Strategies for When to Start HIV Therapy*, available at 1-800-822-7422 or www.projectinform.org.

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Interventions against HIV

Many things can influence your life with HIV. Some are out of your hands, for instance, if you've gotten a resistant strain of HIV. You can't change that. However, many others are under your control in addition to taking HIV meds, highlighted in the 5 areas below. Many find combining the best aspects from each of these areas that suits their lifestyle go a long way in keeping them healthy over time. The biggest mistake is to rigidly choose one over the exclusion of the others.

GENERAL HEALTH

A good defense to HIV builds upon a solid foundation of general health. This means doing all of the things that our doctors normally recommend to lead a healthy life: eat properly; get enough rest; avoid alcohol, smoking, drugs and unnecessary stress; and exercise. Good general health will help you recover more quickly from occasional illnesses. For more information, read Project Inform's publication, *Strategies for Maintaining Your General Health*.

SUPPORTIVE THERAPIES

Supportive or "holistic" therapies can help you deal with symptoms of illness or drug side effects and keep your peace of mind. These include stress reduction; massage; visualization, yoga and relaxation; emotional and spiritual support; natural medicines; and many others. One should consider these as ways to *complement* medical care rather than *replace* it. For

more information, read Project Inform's publication, *Herbs, Supplements and HIV Disease*.

HIV TREATMENT STRATEGY

When used together in rational combinations, HIV meds can suppress the virus for many years and lengthen your life. The challenge of using these drugs is knowing when and how much to use, how to combine them, and in what order. For more information, read Project Inform's publication, *Strategies for Starting HIV Treatment*.

IMMUNE THERAPIES

The goal of using immune therapies is to increase the number and function of immune cells or to reduce the number of infected cells. Some influence the immune system, though to date they haven't proven effective in fighting HIV. And similar claims are made about some natural products that somehow "boost the immune system". There's little evidence that

anyone really knows how to do this. The best way to protect the immune system is to make informed decisions about HIV therapy. For more information, read Project Inform's publication, *Strategies for Improving Your Immune Health*.

OPPORTUNISTIC INFECTION STRATEGY

As the immune system weakens over time, it's necessary to try to prevent the most common OIs, or prevent them from coming back. This should be considered when CD4 counts near 300 or less, when PCP is possible. The risk of other infections, like CMV and MAC, increase dramatically when CD4s fall below 100. The careful and timely use of medicine can help prevent these and other diseases like TB. Project Inform's publication can help sort this out: *Strategies for Managing Opportunistic Infections*.

