



Published on The Well Project (<https://www.thewellproject.org>)
<https://www.thewellproject.org/hiv-information/considerations-starting-hiv-treatment>

Considerations Before Starting HIV Treatment

Submitted on Sep 15, 2023

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Table of Contents

- [Preparing for HIV Treatment](#)
- [Starting Sooner Rather than Later](#)
- [The Right Health Care Provider](#)
- [Knowledge About HIV](#)
- [A Positive Attitude](#)

Preparing for HIV Treatment

Are you living with HIV? If so, treatment with HIV drugs can improve your quality of life and help you stay healthier longer. But starting treatment is a big decision. To get the most benefit from HIV drugs, they must be used just the way they are prescribed. Taking your treatment correctly is as important as which drugs you and your health care provider choose. So, before you get started, it is important to be prepared and commit to taking your HIV drugs the right way, every day, for your own health. This takes a combination of the right health care provider, enough knowledge about HIV, and a positive attitude.

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Starting Sooner Rather than Later

The results of a study called the START trial have shown once and for all that people living with HIV who start treatment earlier, while their CD4 counts are still high, have a much lower risk of illness and death. This includes people living with HIV who feel well. The study showed that taking HIV drugs earlier reduced the likelihood of developing both [AIDS-related](#) and non-AIDS related illnesses. These results led scientific experts and policy makers to come together in July 2015 and issue a consensus statement declaring that all people living with HIV should have access to HIV treatment as soon as they are diagnosed.

Benefits of Starting Early:

- A longer life
- Having a higher [CD4 cell count](#) and keeping it high
- Preventing further damage to the [immune system](#)
- Decreasing the risk of HIV-related and non-HIV-related health problems
- Reducing your risk of [transmitting \(passing\) HIV](#) to others (also known as [Treatment as Prevention](#)), including babies (through perinatal transmission, or [mother-to-child transmission](#))
- [Eliminating your risk of transmitting HIV](#) to your sexual partners if you take your HIV drugs consistently and your viral load stays undetectable (below the level at which it can be detected with standard tests).

Risks of Starting Late:

- A shorter life

- Having a severely weakened immune system. This can mean that it takes longer to restore your immune system to full strength and you to full health. Recent studies have shown that delaying treatment can increase the chances that people living with HIV will develop AIDS and other serious illnesses.
- Having an increased chance of [immune reconstitution syndrome](#) (can cause worsening of some infections when you begin taking HIV drugs and have few CD4 cells)
- Passing HIV to others, including sexual partners and babies, if you become [pregnant](#)

Treatment Guidelines

Guidelines for HIV treatment are issued by a variety of global and national agencies. They provide a lot of useful information to help health care providers and people living with HIV decide when to start, what to start with, and when to change HIV medications. They also help providers and people living with HIV choose among the many available HIV drugs. Guidelines are written and reviewed regularly by groups of HIV experts, including researchers, healthcare providers, and community activists.

The US Department of Health and Human Services (DHHS) HIV treatment [guidelines](#) recommend that all people living with HIV take HIV drugs, no matter their CD4 count. Since 2015, the World Health Organization (WHO) and other organizations agree with that recommendation.

The Right Health Care Provider

Health care providers who spend most of their time on HIV care are best able to manage this condition.

Ideally, you and your health care provider are a team working together to make the best treatment decisions for you. It is also ideal for you to be able to choose among different providers. Unfortunately, for many people living with HIV, neither of these situations is true. Becoming informed about HIV treatment can help empower you to discuss your condition and your options with your health care provider, whether you were able to choose that person for yourself or not.

Even if you are limited to a specific health care provider, you may want to ask yourself a few questions about your relationship with them:

- Can I be totally honest with my provider?
- Are they available when I have questions?
- Do they take my concerns seriously?

If so, great! If not, you may want to make some changes. Although it can be difficult, you may want to ask your provider directly if they will be available for questions. If you do not feel fully respected or taken seriously, you may want to talk to your provider. You may want to tell them that you are concerned that your relationship is not as strong as it could be because of how you feel they are behaving. It may help to write down the questions you would like to ask your health care provider before you go to visits. Finally, it is always important to answer your provider's questions with the truth, not with what you think they want to hear. If these steps still do not work, it may be time to look for another provider if that is possible.

If possible, it is also wise to have a health care provider who is an HIV specialist. Health care providers who spend most of their time on HIV care are best able to manage this condition. Helpful suggestions for HIV specialists near you can come from friends and/or ASOs (AIDS Service Organizations), or by checking with the American Academy of HIV Medicine (AAHIVM). To find an ASO in your area, [click here](#) or look at [AAHIVM's Referral Link](#). You can also check with the [International Association of Providers of AIDS Care](#).

Knowledge About HIV

The Basics

HIV is a virus that destroys [CD4 cells](#). CD4 cells are part of the body's [immune system](#). The immune system protects the body from germs, such as bacteria, fungi, and viruses. When the immune system loses too many CD4 cells, it becomes weak and can no longer fight off germs, leading to [opportunistic infections](#) (OIs) that can cause serious illness or death.

HIV Treatments

Scientists have developed drugs that stop HIV from making copies of itself (multiplying) in your body. These drugs are grouped into classes. Each class of drugs works to stop HIV at a certain point in its life cycle. There are several classes of HIV drugs:

- Entry inhibitors (including fusion inhibitor, attachment inhibitor and CCR5 antagonist)
- Post-attachment inhibitor
- Integrase inhibitors
- Nucleoside/nucleotide reverse transcriptase inhibitors ("nukes" or NRTIs)
- Non-nucleoside reverse transcriptase inhibitors ("non-nukes" or NNRTIs)
- Protease inhibitors (PIs)
- Capsid inhibitor
- Boosting agents

HIV drugs are always used in combination to attack the virus at different points in its life cycle. This usually means using drugs from at least two different classes. Combining HIV drugs is the best way to reduce the amount of HIV in your blood ([viral load](#)). Fixed-dose combinations include more than one HIV drug in a single pill. Our fact sheet on [HIV Drugs and the HIV Lifecycle](#) has more information about HIV medications.

Baseline Blood Tests

Before you start HIV treatment, your health care provider will take blood for a number of tests. These are your original, or baseline, tests. Future test results will be compared to your original results to see how you are doing and how well your treatment is working.

CD4 cell (T-cell) count: The [CD4 count](#) checks the strength of your [immune system](#). After you start HIV treatment, if your CD4 count is low, you should see it go up. Your CD4 count should be checked every three to four months, if possible. Once this count has become stable, it should be checked every six months to one year.

Viral load test: The [viral load](#) test measures the amount of HIV in your blood. After you start HIV treatment, you should see your viral load go down. Your viral load should be checked about a month or so after you start or change HIV drugs. After that, it should be checked every three to four months until it becomes undetectable in your bloodstream (there is too little virus to detect with standard tests). Once your viral load stays undetectable, it should be checked every six months.

Resistance test: The [resistance test](#) helps determine which drugs are likely to work against the strain of HIV that you have. Experts recommend that everyone get a resistance test before starting or changing HIV treatment.

Other tests to check your overall health: These include [complete blood count \(CBC\)](#), chemistry screen, [lipid profile](#) (cholesterol and fat), [liver](#) tests, and [glucose](#) (blood sugar). Your health care provider should talk with you about how often these tests need to be done.

Treatment Goals

- To get your viral load as low as possible for as long as possible
- To preserve or improve the health of your immune system by increasing the number of CD4 cells
- To improve your quality of life and reduce illness
- To reduce your risk of [passing \(transmitting\) HIV](#) to others

Adherence

Whenever you start treatment, you need to take your drugs on schedule and exactly as prescribed. This is called [adherence](#). To get the most benefit from HIV therapy, good adherence is required. This is so because HIV drugs need to stay at a certain level in your body to fight the virus. If the drug level falls, HIV may have a chance to fight back. Skipping doses, not taking the drugs on time, and not following food requirements can all cause your drugs to be less effective or to stop working altogether.

Resistance

After starting HIV drugs, you should see your viral load decrease and your CD4 cells increase. Over time, however, some people see their viral load increase, even though they are still taking HIV drugs.

When a drug can no longer fight HIV effectively, the virus has become "resistant" to that drug. If you develop [resistance](#), you will likely have to change some of the drugs in your regimen (the combination of different medications that you are taking). If your viral load goes up while you are still taking your HIV drugs, your health care provider should offer you a resistance test. This test will help your provider find out which drugs are not working and help choose ones that will. For some people with resistance to many HIV drugs, it may be difficult to find a new combination.

The best way to fight resistance is to take your HIV drugs exactly as directed.

A Positive Attitude

When you think about starting treatment, it is important to have a good attitude. It can be helpful to know that:

- starting treatment is the right decision for you
- the HIV drugs will help you fight the virus
- you can take your medications the right way

Put together a support system that may include your health care provider, social workers, case managers, family, and/or friends

It may also help to think about the reason why you are starting treatment – to keep yourself in good health, whether for your own sake or for the good of your family, friends or community. Think about it this way: when you have a urinary tract infection, your provider does not wait until it has spread to your kidney or blood stream before treating you. The same is true for acquiring HIV. You need not wait until your immune system is damaged before taking HIV drugs. Newer HIV drugs are much easier on your body and have fewer side effects than the older drugs.

When you think about starting treatment, it is also important not to go it alone. Put together a support system that may include your health care provider, social workers, case managers, family, and/or friends. You may also want to consider joining a [support group](#) of other people living with HIV. Many people living with HIV find support through online communities. Our global community of women sharing their stories of living with HIV is called [A Girl Like Me](#).

Whatever you decide to do, it is important that you keep going to your health care provider for regular checkups; discuss any side effects you may be experiencing so that they can be treated; and remain focused on staying healthy.

Additional Resources

Select the links below for additional material related to considering treatment.

- [Starting HIV Treatment \(POZ\)](#)
- [Newly Diagnosed With HIV \(TheBody.com\)](#)
- [Get Set for HIV Treatment \(aidsmap, personalized tool\)](#)
- [Starting ART – and Using Meds for the First Time \(i-base\)](#)
- [My First Pill: Starting HIV Treatment for the First Time \(TheBody.com\)](#)
- [HIV Treatment: When to Start HIV Medicines \(HIVinfo\)](#)
- [Vancouver Consensus Statement Calls for Early Access to Treatment and PrEP Worl...](#)
- [Your Guide to HIV Treatment: Starting Treatment \(CATIE\)](#)
- [Activists Worldwide Call for Immediate HIV Treatment \(Health-e News, South Afri...](#)
- [Starting HIV Treatment: 7 Important Questions and Answers \(TheBody.com\)](#)
- [What Does an HIV Treatment Plan Look Like \(WebMD\)](#)
- [Starting HIV Treatment \(aidsmap\)](#)
- [Treatment Decisions for HIV \(US Department of Veterans Affairs\)](#)
- [When to Start HIV Treatment \(Terrence Higgins Trust, United Kingdom\)](#)
- [How Does HIV Treatment Work? \(Be in the Know\)](#)



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