

Considerations Before Starting HIV Treatment ^[1]

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Preparing for HIV Treatment

Are you living with HIV (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. In order 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 recent study (the START trial) have definitively shown 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 may have no outward signs of ill

health. The study showed that taking HIV drugs earlier reduced the likelihood of developing not only AIDS-related illnesses, but also non-AIDS related illnesses.

Benefits of Starting Early:

- Having a higher CD4 cell count [3] and keeping it high
- Preventing further damage to the immune system [4]
- Decreasing risk for HIV-related and non-HIV-related health problems
- Reducing your risk of spreading HIV [5] to others (also known as Treatment as Prevention [6]), including sexual partners and babies (through perinatal transmission, or mother-to-child transmission [7])

Risks of Starting Late:

- 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 [8] when you begin taking HIV drugs
- Spreading HIV to others, including sexual partners and babies (if you become pregnant [7])

Over the past several years, experts have debated the potential benefits and risks of starting HIV treatment while people are relatively healthy (have high CD4 counts and no signs of ill health). With the results of the START trial, it appears clear that the benefits of starting treatment early outweigh any potential risks. Consequently, scientific experts and policy makers came together in July 2015 and issued a consensus statement declaring that all people living with HIV should have access to HIV treatment as soon as they are diagnosed. This statement was supported by agencies such as the International AIDS Society, the US President's Emergency Plan for AIDS Relief (PEPFAR), and UNAIDS, among others.

Treatment Guidelines

Guidelines for HIV treatment are issued by a variety of global and country-based agencies. They provide a lot of useful information to help health care providers and people living with HIV make decisions about when to start, when to stop, 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 [9] recommend that all people living with HIV take HIV drugs, no matter what their CD4 count.

The World Health Organization (WHO) released new HIV treatment guidelines in September 2015. By October 2015, all internationally-written guidelines were in agreement for the first time since 2006. The DHHS, WHO, EACS (European AIDS Clinical Society), BHIVA (British HIV Association), and the IAS-USA (International AIDS Society USA) all recommend that HIV treatment be offered to all people living with HIV, regardless of their CD4 count.

Starting sooner rather than later is a decision for you to make with your provider, who will look

at a variety of factors, including some baseline blood tests and readiness to start and stick to lifelong treatment (see below).

The Right Health Care Provider

In an ideal world, you and your health care provider are a team working together to make the best treatment decisions for you. You may want to ask yourself a few questions about your relationship with your health care provider: Do I have confidence in my provider? Can I be totally honest with him or her? Is she or he available when I have questions? Does he or she 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 she or he will be available for questions. If you do not feel fully respected or taken seriously, you may consider telling your provider that you are concerned that your relationship is not as strong as it could be because of how you feel. 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 she or he wants to hear. If these steps still do not work, it may be time to look for another provider.

It is also wise to have a health care provider who is an HIV specialist. Health care providers who devote most of their time to HIV 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](#) ^[10] or look at the [AAHIVM's Referral Link](#) ^[11]. For services worldwide, please use AIDSmap's [e-atlas](#) ^[12].

Knowledge About HIV

The Basics

HIV is a virus that destroys CD4 cells ^[3]. CD4 cells are part of the body's immune system ^[4]. The immune system protects the body from germs such as bacteria, fungi, and other viruses. When the immune system loses too many CD4 cells, it becomes weak and is unable to fight off germs, leading to opportunistic infections ^[13] (OIs) that can cause serious illness or death.

HIV Treatments

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

- Entry inhibitors (including fusion inhibitors and CCR5 antagonists)
- Integrase inhibitors
- Nucleoside/nucleotide reverse transcriptase inhibitors ("nukes" or NRTIs)
- Non-nucleoside reverse transcriptase inhibitors ("non-nukes" or NNRTIs)
- Protease inhibitors (PIs)
- 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 [15]).

Baseline Blood Tests

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

1. **CD4 cell (T-cell) count:** The CD4 count [3] checks the strength of your immune system [4]. After you start HIV treatment, you should see your CD4 count go up. Your CD4 count should be checked every three to four months, if possible, then every six months to one year, once it has become stable.
2. **Viral load test:** The viral load [15] 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 after you start or change HIV drugs. After that, it should be checked every three to four months, then every six months, once it has become undetectable in your bloodstream and stays undetectable.
3. **Resistance test:** The resistance test [16] helps determine which drugs are likely to work against the strain of HIV you have. Experts recommend that everyone get a resistance test before starting or changing HIV treatments, even if you do not plan to start HIV treatment for a while.
4. **Other tests to check your overall health:** These include complete blood count (CBC) [17], 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 your CD4 cells
- To improve your quality of life and reduce illness
- To reduce your risk of spreading HIV [5] to others

Adherence

Whenever you start treatment, you need to take your drugs on schedule and exactly as prescribed. This is called adherence [18]. In order to get the best benefit from HIV therapy, good adherence is required. This is because HIV drugs need to be kept 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 is no longer able to fight HIV effectively, HIV has become "resistant" to that drug.

If you develop [resistance](#) [19], you will likely have to change some of the drugs in your regimen. If your viral load goes up while you are still taking your HIV drug regimen, your health care provider should offer you a resistance test to find out which drugs are not working and to 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 considering starting treatment, it is important to have a good attitude. It can be helpful to believe 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

It may also help to get in touch with the reason you are starting treatment ? to keep yourself in good health, whether for your own sake or for the good of your family. Think about it this way: when you have a bad sore throat and need antibiotics, your provider does not wait until you have pneumonia before giving you the antibiotics. The same is true for being infected with HIV. You need not wait until your immune system is damaged before taking HIV drugs. Newer HIV drugs are much better tolerated and have fewer side effects.

When you consider 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, or friends. You may also consider joining a [support group](#) [20] 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](#) [21].

Whatever you decide to do, it is important that you keep going to your health care provider for regular check ups and remain focused on staying healthy.

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Additional Resources

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

[Starting HIV Treatment \(POZ\)](#) [38]

[How to Locate HIV/AIDS Services Near You \(The Body\)](#) [39]

[Get Set for HIV Treatment \(questionnaire from AIDSmap\)](#) [40]

[Starting HIV Treatment: Kerrigan's Story \(video; CATIE\)](#) [41]

[Vancouver Consensus Statement Calls for Early Access to Treatment and PrEP Worldwide \(AIDSmap\)](#) [42]

[Starting Antiretroviral Treatment Early Improves Outcomes for HIV-Infected Individuals \(NIH\)](#) [43]

[Preparing to Start Treatment \(CATIE\)](#) [44]

[Activists Worldwide Call for Immediate HIV Treatment \(Health E-News\)](#) [45]

[Considering Treatment and Your Health Care \(The Body\)](#) [46]

[HIV Treatment: When to Start Antiretroviral Therapy \(NIH\)](#) [47]

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Links:

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<http://www.thewellproject.org/sites/default/files/Considerations%20before%20starting%20treatment.7.2016.pdf>

[3] <http://www.thewellproject.org/hiv-information/understanding-cd4-cells-and-cd4-cell-tests>

[4] <http://www.thewellproject.org/hiv-information/understanding-immune-system>

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- [10] <http://directory.poz.com/>
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- [12] <http://www.aidsmap.com/e-atlas>
- [13] <http://www.thewellproject.org/hiv-information/what-are-opportunistic-infections>
- [14] <http://www.thewellproject.org/hiv-information/hiv-drugs-and-hiv-lifecycle>
- [15] <http://www.thewellproject.org/hiv-information/women-and-viral-load>
- [16] <http://www.thewellproject.org/hiv-information/understanding-lab-tests-ii-viral-load-resistance-and-tropism>
- [17] <http://www.thewellproject.org/hiv-information/understanding-lab-tests-i-complete-blood-count-and-blood-chemistry>
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- [20] <http://www.thewellproject.org/node/178>
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- [37] <http://www.thewellproject.org/tags/skipping-doses>
- [38] https://www.poz.com/basics/hiv-basics/starting-hiv-treatment?utm_campaign=301_Redirect&utm_source=aidsmeds
- [39] <http://www.thebody.com/content/77661/how-to-locate-hivaids-services-near-you.html>
- [40] <http://www.aidsmap.com/getset#intro>
- [41] <http://www.catie.ca/en/treatment/personal-stories/kerrigan>
- [42] <http://www.aidsmap.com/Vancouver-Consensus-Statement-calls-for-early-access-to-treatment-and-PrEP-worldwide/page/2985626/>
- [43] <http://www.nih.gov/news/health/may2015/niaid-27.htm>
- [44] <http://www.catie.ca/en/practical-guides/hiv-drug-treatment/3-treating-hiv/3-5>
- [45] <http://www.health-e.org.za/2015/07/21/activists-worldwide-call-for-immediate-hiv-treatment/>
- [46] <http://www.thebody.com/content/art58159.html>
- [47] <http://aidsinfo.nih.gov/education-materials/fact-sheets/21/52/when-to-start-antiretroviral-therapy>