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Starting HIV Treatment

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First Things First

When you and your health care provider decide the time is right for you to start treatment, there are things you can do to set yourself up for success. The first step is to think positively. Having the right attitude will help you get the most out of your treatment. It may be helpful to focus on how:

- Starting treatment is the right decision for your health. Recent studies have shown that people living with HIV who start treatment earlier, while their <u>CD4 counts</u> are still high, have a much lower risk of <u>IRIS</u> (immune reconstitution inflammatory syndrome, a condition in which some infections may flare up as the immune system gets stronger), illness, and death.
- HIV drugs will help you fight the virus and prevent damage to your immune system
- You can take your medications the right way

It takes a lot of commitment to stick to a treatment regimen (combination of HIV drugs). There is no need for you to go it alone. Your health care provider is an important support person and so are other people, such as nurses, social workers, therapists, and case managers. You may want to join a <u>support group</u> for people living with HIV or check out our online support community, A Girl Like Me. Family and friends can help, too.

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It can be tough to stick with a treatment regimen if you need to work on other issues in your life. If you feel down a lot of the time and do not enjoy things that you used to enjoy, you may be <u>depressed</u>. If you are depressed or feeling low, it is important to talk with your provider and get the support you need. Studies show that there is a direct connection between depression and poorer health for those living with HIV. Specifically, women living with HIV who are depressed seek HIV care less often, have more trouble sticking with their HIV drug regimens, and their HIV gets worse more quickly.

Keep asking questions! The more you know, the better equipped you are to be successful with your HIV treatment.

Studies have also shown that stigmatizing beliefs and/or fear of stigma keep people from getting and staying in care, getting HIV drugs, and taking these drugs correctly (adherence). To find out more about stigma and how to cope with it, see our fact sheet on Stigma and Discrimination Against Women Living with HIV.

Also talk with your provider if you have issues with <u>substance use</u> or feeling safe in your home (see our fact sheet on <u>Violence Against Women and HIV</u>). Taking care of problems with depression, substance use, stigma, and personal safety can really help you take your HIV drugs regularly and be as healthy as possible.

Important: If you are feeling threatened right now, call 911 or the National Domestic Violence hotline in the US at 800-799-SAFE [1-800-799-7233; or 1-800-787-3224 (TTY)]. You can also search for a safe space online at Domestic Shelters.

It is important to tell your health care provider if you have other health problems, are taking any other drugs (including over-the-counter medications, <u>vitamins or supplements</u>, or street drugs), are using any <u>alternative or complementary therapies (herbals)</u>, or are in any recovery programs. This is important information that may affect your HIV treatment options. In addition, discuss family planning with your health care provider since HIV drugs can interfere with some <u>birth control</u> methods, and <u>pregnant</u> people should not take certain HIV drugs.

Choosing an HIV Drug Regimen

The next step is for you and your health care provider to choose a drug regimen. The drugs approved in the US for HIV treatment are grouped into different classes:

- Nucleoside and nucleotide reverse transcriptase inhibitors (NRTIs)
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs)
- Integrase inhibitors
- Protease inhibitors (PIs)
- Entry and fusion inhibitors
- Attachment inhibitor
- Post-attachment inhibitor
- Capsid inhibitor
- Combination pills
- Boosting agents

Some pills include several drugs from different drug classes. There are many ways to combine the drugs, but experts recommend that in the US, most people who have never taken HIV drugs start with a combination that includes an integrase inhibitor and at least one other drug.

- An integrase inhibitor plus 2 NRTIs (for most people starting treatment);
- A PI plus 2 NRTIs [in most cases the PI should be combined, or "boosted," with a small dose of a second PI called Norvir (ritonavir) or cobicistat; this makes the first PI work better] (may be preferred in certain cases)*;
- An NNRTI plus 2 NRTIs (may be preferred in certain cases)

*Note: The recommendations are different for people who have had long-acting cabotegravir injected to prevent them from acquiring HIV, but have acquired HIV anyway (e.g., because they missed an injection).

See our fact sheet on <u>HIV Treatment Guidelines</u> for more information on recommended treatments in the US and globally.

Resistance

With any HIV regimen, a major problem can be the development of <u>resistance</u>. When HIV makes copies of itself (reproduces), it can make changes, called mutations. Some mutations prevent certain HIV drugs from working. When this happens, HIV has become "resistant" to a particular HIV drug. Your

viral load can increase quickly if resistance occurs, and you may have to switch drug regimens.

In addition, if you become resistant to one drug, you can become resistant to other drugs in the same class more easily. This is known as cross-resistance. The more drugs to which you are resistant, the fewer treatment choices you have.

Resistance Tests

Before starting HIV treatment, it is important that your health care provider do a resistance test to find out if you have a drug-resistant strain of HIV. This helps determine which drugs might work best for you. The US treatment guidelines recommend resistance tests for people who:

- have just been diagnosed with HIV
- are starting HIV drugs
- are switching HIV treatments and their viral load is over 1,000 copies
- have a viral load over 1,000 copies

Sequencing

One of the strategies in HIV treatment is to think ahead. We know that drugs may stop working because of resistance and cross-resistance. When you and your health care provider choose your first regimen, it is also important to think about which drugs could be used in future regimens if your original HIV drugs stop working. This process is called sequencing your treatment. It ensures that you will have other treatment options available if resistance develops.

Adherence

The best way to prevent resistance is with good <u>adherence</u>. Adherence means taking your HIV drugs exactly as directed. This gives the drugs the best chance of working well to keep HIV from multiplying (reproducing). The less HIV can reproduce, the less likely it is to develop mutations that can lead to resistance.

Dosing Schedule

It will be easier to take your drugs exactly as they were prescribed if you set up a dosing schedule that works for you. A dosing schedule is simply a plan for when you take which drugs each day. Ask your health care provider the following questions:

- How many pills are in a dose? How many drugs are in a pill?
- How many times a day should each dose be taken?
- Are there any food requirements (for example, take on an empty stomach or take with food)?
- Are there any drugs or supplements that may interfere with how this HIV drug works?

Then make your plan. If you take drugs in the morning, pick something that you do every morning, like brushing your teeth or having a cup of coffee. Take your drugs at that time.

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If your drugs are twice a day or only in the evening, pick a reminder at night. Maybe you always watch the 11:00 news or have a cup of tea before you go to bed. Whatever you do, add your HIV drugs to your routine!

If you miss a dose of your HIV drugs, take it as soon as you remember that day. However, if you miss a day, do not take a double dose the next day. Take your regular dose again the day following the missed dose.

If you have children, make sure your pill-taking schedule fits in with their routines as well as your own. Keep your drugs in a place where young children cannot reach them. It is also important to plan for weekends and holidays by making sure you have enough of your HIV drugs to last while drug stores are closed or if you go out of town.

You can track how well you are taking your pills by keeping a journal or chart, or using a reminder app on your phone. Remember that everyone makes mistakes. When this happens, it is important to start again and commit to staying on track. If you start missing doses regularly, tell your healthcare provider. He or she can help you identify the problem and come up with a solution.

Taking Your Pills

If no one knows about your HIV status, taking your HIV drugs may be more difficult. You may feel like you have to hide your pill bottles or sneak out of the room when it is time for your dose. These challenges can make it harder to take your drugs. If you remove the original drug labels, it is important to re-label your pill bottles in a way that helps you remember what to take and when to take it.

This may be a good time to <u>tell the people who are close to you about your HIV status</u>. However, if you are not ready, you can put everything in a pillbox and tell people you take vitamins, or medicine for another condition.

Side Effects

All HIV drugs have some <u>side effects</u> (**but not all people experience side effects**). Side effects are one of the major reasons that people do not stick to their HIV regimen. It is best to be prepared by asking your health care provider about the possible short- and long-term side effects of your particular drug regimen.

There are medicines that can be used to treat short-term side effects like nausea and <u>diarrhea</u>. Ask your health care provider to recommend some things you can do to reduce or manage side effects. If you might need medication to manage side effects, it is best to have a supply on hand before you start your HIV drugs.

If you are having side effects, it is important that you not stop your HIV drugs unless your healthcare provider tells you to stop. On the other hand, there is no need to 'grin and bear it.' Instead, contact your healthcare provider and talk to her or him about ways to deal with the side effects. Your provider may suggest switching to another drug combination.

Putting It All Together

Now you are ready to go! As you get started, believe in your ability to stick with your drug regimen. Also, keep asking questions! The more you know, the better equipped you are to be successful with your HIV treatment.

Checklist to discuss with your provider:

Other medications or vitamins you are taking, including over-the-counter, herbal, and street drugs Substance use (drug or alcohol) issues

Whether you are <u>pregnant</u> or <u>plan to get pregnant</u>

If you feel depressed or have experienced mental health issues in the past

What your <u>support system</u> is like and whether you need additional support Resistance testing

Issues/barriers you might have taking your drugs on time every day The dosing schedule of the HIV drugs you will be taking:

- Are there food requirements?
- What are the side effects?
- How many times a day do you take them?
- How many pills are in one dose?

Additional Resources

Select the links below for additional material related to starting HIV treatment.

- Starting HIV Treatment (aidsmap)
- Starting HIV Treatment (POZ)
- How HIV Treatment Works (Be in the Know -Avert)
- HIV/AIDS Resource Center for the Newly Diagnosed (TheBody.com)
- HIV Treatment Recommendations (POZ)
- Start and Continue HIV Meds as Soon as You Can (San Francisco AIDS Foundati...
- Starting HIV Treatment: 7 Important Questions and Answers (TheBody.com)
- Following an HIV Treatment Regimen: Steps to Take Before and After Starting HIV...
- HIV and AIDS: Medicines to Help You (US Food and Drug Administration)
- HIV Treatment (US Centers for Disease Control and Prevention)
- When to Start HIV Medicines (HIVinfo)
- Introduction to ART (i-base)
- What to Expect When Beginning Treatment for HIV/AIDS, Explained by an Expert (S...
- When to Start HIV Treatment (Terrence Higgins Trust, UK)



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