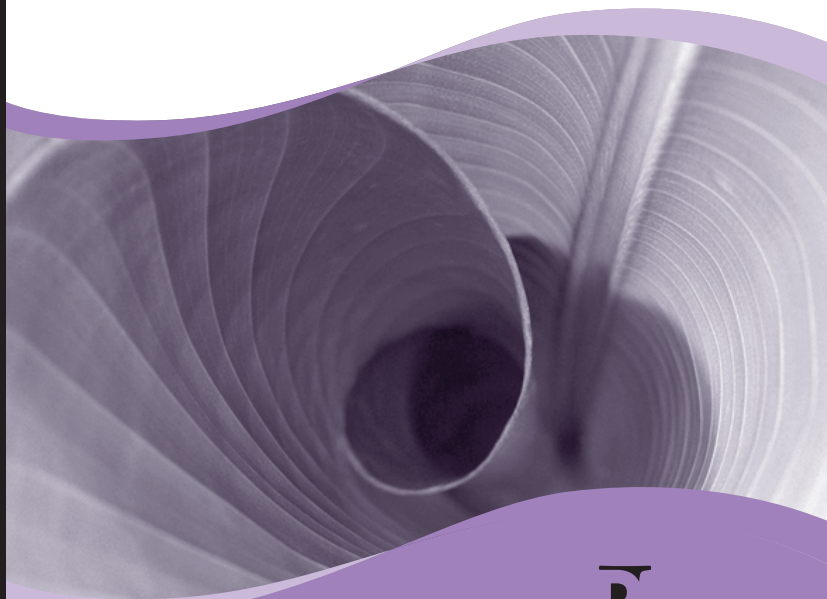


ATTAINING HIV HEALTH & WELLNESS:

What you should know about when to start and what meds to use

- get informed
- ask questions
- live well




PROJECT
INFORM

JULY 2011

ATTAINING HIV HEALTH & WELLNESS

Project Inform created this series of three publications to address commonly asked questions and issues that people face as they come to terms with their HIV status and begin addressing their health care needs.

After you've tested positive

Booklet 1 helps guide individuals on basic things to do after an HIV diagnosis, with an emphasis on understanding HIV infection, getting into care, and finding a support network.

Considering treatment & your health care

Booklet 2 explores making decisions, from considering treatment to talking things out with a support network and doctors to thinking broadly about personal health needs.

What you should know about when to start & what to use

Booklet 3 focuses on issues related to taking HIV medications, including when to start and what to use, planning ahead and finding an HIV-experienced doctor. (Some sections contain scientific concepts and information.)



*Project Inform acknowledges Liz Highleyman
for her review and edit of these materials.*

Table of contents

| | |
|--|---|
| Using this booklet ... | 3 |
| How is today different from earlier in the epidemic? | 4 |

KNOWLEDGE: Understanding the details of treatment

| | |
|---|-------|
| When to start: general issues | 6–7 |
| HIV treatment Guidelines | 8 |
| When to start: CD4 count ranges | 9–11 |
| The possible benefits of starting at 350–500 CD4s | 12 |
| The possible risks of starting at 350–500 CD4s | 13 |
| The START study | 14 |
| The classes of HIV meds | 15 |
| A brief overview of the five classes of HIV drugs | 16–17 |
| Choosing your first and maybe second regimen | 18 |
| Recommended regimens for first line treatment | 19 |

HEALTH: Your ability to start and maintain

| | |
|-----------------------------|-------|
| Keeping up with taking meds | 21 |
| Side effects | 22 |
| Drug interactions | 23 |
| Women and HIV treatment | 24–25 |
| Power of the mind | 26 |

SELF-ADVOCACY: Getting ready to start

| | |
|---|-------|
| Is your doctor experienced in treating HIV? | 28 |
| Important questions | 29 |
| Managing your quality of life | 30–31 |

RESOURCES:

| | |
|-------------------------------|----|
| Checklist for getting started | 32 |
| Personal tracking chart | 33 |



**"MY HEALTH GOT
BETTER WHEN I TALKED
ABOUT MY HIV."**

CALL US. WE HAVE TIME TO TALK.

HIV HEALTH INFOLINE

Monday–Friday, 10am–4pm (Pacific Time), in English & Spanish

1.866.HIV.INFO (448.4636) TOLL-FREE

Our operators live with or are impacted by HIV, and provide valuable insight and support to callers by answering questions about HIV care and making referrals to local services.

www.projectinform.org/HIVhealth/

**PROJECT
INFORM**
25 YEARS OF SUPPORTING
PEOPLE LIVING WITH HIV

Using this booklet ...

Getting the earliest possible treatment is generally recommended for most illnesses. HIV may not be any different; except that once it's started, treatment is for life. But knowing the best time to start HIV meds is the subject of a great deal of debate and theory. On one hand, the question can be a matter of personal choice. But on the other, a growing body of evidence shows it may be more beneficial to start earlier.

Some experts believe that starting treatment is appropriate immediately after finding out your HIV diagnosis. Waiting might allow the virus to progress further and do more damage to your immune system. Starting earlier may prevent losing important CD4 cells that direct immune function.

However, some doctors recommend starting later. They believe it's better to save drugs for later, when symptoms of disease or damage to the immune system have shown. In this case, treating too early may “use up” the drugs before they're most needed.

People may also have long-term side effects from the drugs before they're most needed. Since HIV drugs have not been used over several decades, their true long-term effects are unknown. Most doctors would agree that it's necessary to start meds when HIV symptoms are present, your CD4 count is falling, or your viral load is high and rising.

Whether you start earlier or wait, your willingness to commit to treatment over the long-term, as well as learning about all your options ahead of time, will influence how well you do. Unless you were diagnosed with late-stage disease, you likely have time to get informed about when to start and what meds to use. This booklet can help. We offer this information to help support, but not replace, the relationship with your health provider.

HELPFUL RESOURCES

HIV Health InfoLine 1-800-822-7422, 10a-4pm, M-F, PST

How is today different from earlier in the epidemic?

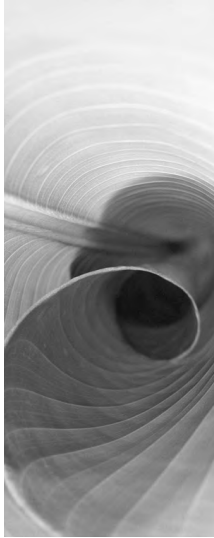
Treating HIV is very different today than what it was earlier in the epidemic. People are now healthier and living longer on HIV meds, and many can start with a full regimen of just one or two pills taken once or twice a day. The days of taking 30 pills a day are over for most. There are also fewer food restrictions. You have more drugs to choose from and they're generally easier to take and tolerate.



Perhaps some of the things you believe about today's medicines are not — or are no longer — true. Concerns still linger in the community about severe side effects and how someone may look after being on meds for awhile. Newer regimens generally have fewer and more manageable side effects, both in the short-term and over time. This doesn't mean that you won't have side effects, but in general they occur less often and are less severe. The drugs that caused the most problems are now seldom used for people starting treatment.

While body shape changes such as sunken cheeks, extended belly or enlarged breasts still occur in some people, they happen less often and to a lesser degree today. The early NRTI drugs like Videx and Zerit contributed to fat loss in the face, arms and legs (called *lipoatrophy*). Newer drugs generally cause less of this.

What hasn't changed is that HIV remains a serious condition. Although HIV meds cannot get rid of the virus completely, they slow the course of disease, preserve health and quality of life, and improve survival.



KNOWLEDGE:

Understanding
the details of
HIV treatment

WHEN TO START: some general issues

Some people will start HIV treatment right away, while others may wait for awhile. The following factors can help you and your provider choose the best time to start.

YOUR CD4 COUNT TREND

A trend is when you look at two or more CD4 count results to see how much they change. Over time, falling CD4s indicate declining immune health. There's general agreement that a loss of 100 CD4s or more each year shows a weakening immune system. Don't panic about a single lower test result, but consult with your doctor and consider another test to determine your trend.

The CD4 percentage trend is also useful to consider. This tends to change less often between tests than the CD4 count, so it may be more reliable.

YOUR VIRAL LOAD TREND

Consistently increasing HIV levels indicate that the virus is reproducing and can infect more CD4s, which causes more damage to the immune system. Again, the trend over time is important: consider two or more viral load test results to inform a treatment decision. Experts generally agree that an increase in viral load to above 100,000 is a sign to start treatment, independent of CD4 count.

YOUR GENERAL HEALTH

Your general health and whether or not you have minor symptoms can also help determine when to start. If your health is good and stable, then starting treatment right away

may not be necessary. But if you have some symptoms of HIV disease, despite a good CD4 count, starting might be the better decision. On the other hand, if you have an illness that makes it difficult to adhere to or manage the side effects from the HIV drugs, it may be better to wait until you're feeling better and the other illness has resolved. Your doctor can help you make this decision.



ARE YOU READY TO START?

You should begin treatment when you feel you're ready for the demands of life-long treatment. This includes being emotionally ready, as well as being able to take pills every day, manage possible side effects, and ensure you have steady access to health care. It may mean you first need to address other issues such as finding stable housing or mental health or substance use services. Without a strong commitment to and support for taking your pills as prescribed, you're less likely to get the best outcomes.

MAIN POINTS TO REMEMBER:

- A decreasing CD4 count and/or percentage may indicate a need to start treatment, especially 100 or more CD4s within 12 months.
- An increasing viral load, especially above 100,000, indicates to start treatment.
- Think about other aspects of your life, including your general health, and how treatment may impact them.

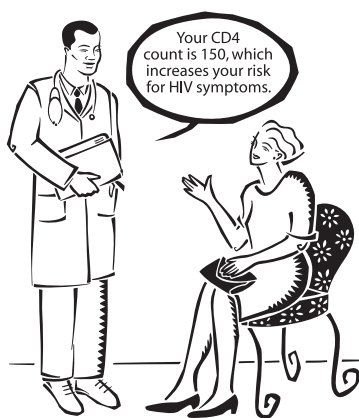
HIV treatment guidelines

The US Department of Health and Human Services *Guidelines* for treating HIV infection are updated periodically, the last time in December 2009. They're meant to help guide people with HIV and their doctors through the issues that may arise when choosing and using HIV meds, including when to start and what drugs to use. The Guidelines are based on the latest research as interpreted by a panel of experts, which result in recommendations, not rules. When enough information is known about some aspect of treating HIV disease, the Guidelines will recommend or suggest a preference. When data are less clear, they will state just that.

The *Guidelines* state that HIV treatment should be based on a person's own unique situation, best done with the expert advice of an experienced doctor. Important details from the Guidelines about when to start and what meds to choose are found over the next several pages.

The following conditions increase the urgency to start:

- CD4 count below 200
- loss of more than 100 CD4s each year
- viral load above 100,000
- AIDS-defining illness
- certain OIs, such as cryptosporidiosis
- pregnancy
- HIV-related kidney disease, called HIVAN
- hepatitis B virus co-infection that requires treatment



When to start: CD4 count ranges

Pages 11–15 go more in-depth about the clinical research behind starting treatment based on certain CD4 count ranges.

A brief, basic explanation of clinical studies

This section mentions two types of studies, both of which can provide important information about HIV treatment.

Randomized studies are considered the “gold standard” of clinical research. By randomly putting people in different groups or *arms*, they balance both known and unknown factors, and limit biases that may influence their outcomes.

Observational and **cohort studies** are less rigorous and do not randomize or control study arms. For example, a study might look at a group of people who have heart attacks and see what they have in common. While these studies can produce useful information, they may not be able to limit biases or unknown factors as well as randomized studies.

STARTING TREATMENT DURING EARLY INFECTION

There’s not as much research on starting HIV drugs in the first few months or even first year of infection. Many, if not most, people do not have to decide this soon after their diagnosis. However, it’s reasonable for people to start at this time if they believe it will benefit them. Starting early may prevent damage from HIV, including loss of CD4s and problems related to inflammation.

On the other hand, starting immediately after infection may not give you enough time to fully learn about the risks and benefits of long-term treatment. Starting early risks “using up” HIV medications sooner, as well as long-term side effects and drug resistance.

HELPFUL RESOURCES

Options Project <http://labs.ucsf.edu/options/>

When to start: CD4 counts, *continued*

STARTING TREATMENT AT 200 CD4 CELLS OR BELOW

The *Guidelines* state that treatment should be started when CD4s are below 200, which constitutes an AIDS diagnosis. If you're in this range at diagnosis, HIV treatment can greatly improve your health and CD4 count, and help prevent AIDS and other health conditions. Results from several randomized and long-term observational studies clearly show that waiting until CD4s drop below 200 greatly increases the risk of OIs, other health conditions and death. More study results support starting treatment in this CD4 range than at any other level.

STARTING TREATMENT BETWEEN 200–350 CD4 CELLS

The *Guidelines* state that treatment should also be started when CD4s are in this range. If you're in this range at diagnosis, HIV treatment can improve your health and CD4 count, and help prevent AIDS and other health conditions. A few randomized studies show more benefit to starting in this range than waiting to start at 200 or below. For example, the CIPRA study showed a significantly higher rate of death and TB in people who started below 200 vs. those who started below 350. Also, a sub-study from the SMART study showed a lower risk of AIDS and non-AIDS conditions in people who started HIV meds with CD4s above 350 vs. those with less than 250 CD4s.

STARTING TREATMENT BETWEEN 350–500 CD4 CELLS

The *Guidelines* state that treatment is recommended in this range, although the expert panel was divided on the strength of this recommendation. While the panel agreed that the risk of death or serious illness is low overall, no randomized studies have conclusively shown to start in this range.

Results from some large observational studies suggest benefits to starting in this range. The ART-CC study showed a lower rate of AIDS and death in people with 350–450 CD4s vs. those with

When to start: CD4 counts, *continued*

250–350 CD4s. NA-ACCORD and CASCADE showed an increased risk of death for people who started treatment below 350 vs. 350–500. What limits these studies is that the overall numbers of AIDS cases and deaths were small. They also didn't evaluate the impact of adherence, resistance or long-term side effects.

Other studies show that starting in this range leads to higher CD4 counts. The ATHENA cohort showed that people who start with CD4s above 350 will more likely reach a level above 800. The John Hopkins cohort showed that those who started at below 350 CD4s are less likely get their count above 500. Further, there's growing evidence to suggest that damage to various organs is possible due to inflammation from untreated HIV at most any CD4 level. (Read important details about this range, pages 12–13.)

STARTING HIV TREATMENT ABOVE 500 CD4 CELLS

In the US, the average CD4 count at diagnosis is about 340. Yet, some people consider starting when their CD4s are above 500. No randomized and few observational studies show an advantage for starting above 500. CASCADE showed a benefit in the 350–500 range but not above 500. Some experts think starting HIV meds above 500 might limit damage to the immune system and organs due to inflammation. The Guidelines panel was split: half favored starting in this range while half thought it was optional. Although it's reasonable for someone to start above 500, the pros and cons should be carefully considered as the risks and benefits are not yet known. The new START study will help answer this question (see page 14).

HELPFUL RESOURCES

When Should I Start Treatment, and What Should I Start First?

www.aidsmeds.com/articles/WhenToStart_7512.shtml

DHHS Guidelines www.aidsinfo.nih.gov/guidelines/

Possible benefits of starting treatment at 350–500 CD4s

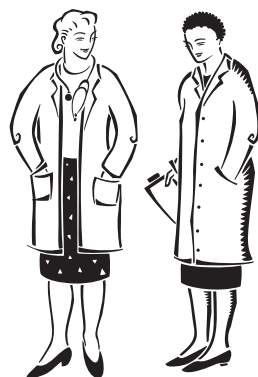
- An increasing number of observational results and early clinical studies suggest lower rates of AIDS and other health related conditions and death.
- Current first line regimens are more effective and easier to take and tolerate, which helps improve adherence.
- People who start above 350 are better able to achieve and maintain higher CD4s over time than those who start below 350.
- People with better overall health tend to have an easier time tolerating medicines.
- Reduces the risk of early damage to the immune system.
- Reduces, though does not eliminate, inflammation.
- Untreated HIV, even at higher CD4s, may contribute to heart, liver, kidney, brain and other organ diseases and cancers.
- Starting in this range reduces the transmission of HIV, based on several studies of mixed HIV status, heterosexual couples.
- Early treatment may decrease overall cost of health care by avoiding more serious conditions later.

Possible risks of starting treatment at 350–500 CD4s

- Randomized studies have not been done, which would provide more solid evidence of an added benefit.
- The ART-CC and NA-ACCORD studies included many people who were taking regimens used less often today and did not assess the impact of long-term side effects, adherence or drug resistance.
- Some studies show a higher risk of heart disease with continued use of certain NRTIs and PIs; higher rates of bone loss are linked to longer time on treatment.
- Some long-term side effects of newer HIV meds are not known and may not appear until 10 or more years of use.
- Possible side effects may decrease the quality of life for otherwise healthy people.
- Starting in this range increases the risk of earlier resistance, which may lead to running out of options.
- The current pipeline of experimental HIV meds is thin and may not produce many more drugs soon.
- Starting in this range may add 2–3 more years of total time on treatment.
- Starting in this range increases the risk of treatment fatigue, which could lead to poor adherence.
- The current economy may make it difficult for some people to access public programs like ADAP to cover the cost of their meds and blood work.
- Results from START will not be available until 2014.

The START study

So far, there have not been any results from randomized, controlled studies to guide decisions about when to start treatment above 350 CD4s. Such a study has been a topic of much debate, and only recently has one gotten off the ground, appropriately named START (Strategic Timing of AntiRetroviral Treatment). This study will enroll nearly 4,000 people in about 30 countries.



In START, people will either begin treatment with CD4s above 500 or wait until their CD4s fall to below 350. The study will assess whether people are more or less likely to result in a serious AIDS condition, other health condition or death at various CD4 levels. Sub-studies will be done to collect information on issues such as inflammation, neurological problems, and bone, heart and liver health.

The final results are expected around 2014, with interim reports probably presented before then. Researchers expect the study to provide a clearer understanding of both the benefits and risks of starting treatment at different CD4 counts, especially long-term side effects and drug resistance.

MAIN POINTS TO REMEMBER:

- START is the only randomized controlled study to conclusively guide decisions to start treatment when CD4s are above 350.
- The final results from START won't be available until 2014.
- In some cases, it's reasonable for some people to wait until these results are known before starting.

HELPFUL RESOURCES

INSIGHT START 001 study <http://insight.cabr.umn.edu/start/>

Clinical Trials.gov www.clinicaltrials.gov

Classes of HIV meds

Your first regimen will probably include three drugs from two different classes. These classes work against different steps in the life cycle of HIV, so using at least two classes together reduces the risk that HIV will become resistant. Combining meds in this way will provide better and longer-lasting health outcomes.

Below is the current list of HIV meds, organized by class and then listed alphabetically by brand name, along with their generic names, three-letter abbreviations, and year of FDA approval. Some drugs are no longer used or not used often in the US, while others are used only in special circumstances.

NRTIs (nucleoside/nucleotide reverse transcriptase inhibitors)

Emtriva (FTC, emtricitabine, 2003)
EpiVir (3TC, lamivudine, 1995)
Retrovir (AZT, zidovudine, 1987)
Videx EC (ddI, didanosine, 2004)
Viread (TDF, tenofovir, 2001)
Zerit (d4T, stavudine, 1994)
Ziagen (ABV, abacavir, 1998)

PIs (protease inhibitors)

Aptivus (tipranavir, 2005)
Crixivan (indinavir, 1996)
Invirase (saquinavir, 2003)
Kaletra (lopinavir/r, 2000)
Lexiva (fosamprenavir, 2003)
Norvir (ritonavir, 1996,
currently used as a booster)
Prezista (darunavir, 2006)
Reyataz (atazanavir, 2003)
Viracept (nelfinavir, 1997)

NNRTIs (non-nucleoside reverse transcriptase inhibitors)

Eduvant (rilpivirine, 2011)
Intelence (etravirine, 2008)
Rescriptor (delavirdine, 1997)
Sustiva (EFV, efavirenz, 1998)
Viramune (nevirapine, 1996)

ENTRY INHIBITORS

Fuzeon (T20, enfuvirtide,
injectable, 2003)
Selzentry (maraviroc, 2007)

INI (integrase inhibitor)

Isentress (raltegravir, 2007)

FIXED DOSE COMBINATIONS

Atripla (TDF+FTC+EFV, 2006)
Combivir (AZT+3TC, 1997)
Epzicom (3TC+ABV, 2004)
Trizivir (AZT+3TC+ABV, 2000)
Truvada (FTC+TDF, 2004)

HELPFUL RESOURCES

AIDSMeds.com www.aidsmeds.com/list.shtml

A brief overview of the five classes of HIV drugs for *first line therapy*

NRTIs (nucleoside reverse transcriptase inhibitors)

This class is currently used as the “backbone” of most HIV regimens, and two are normally taken with one drug from another class. One combo pill, Truvada, is a *preferred* choice in the Guidelines. Two others, Epzicom and Combivir, are *alternatives*. Regimens with three NRTIs but no other drug class are not recommended, and there’s not enough data yet about regimens without NRTIs.

Viread (also in Truvada, Atripla) may cause kidney problems and bone loss in some people. These are somewhat uncommon but they may be serious when they do occur. Ziagen (also in Epzicom, Trizivir) can cause a serious allergic reaction in a few people, for which an *HLA test* can predict your risk. Ziagen may also increase the risk of heart attacks, but studies so far show conflicting results. Retrovir (also in Combivir, Trizivir) causes more fat loss in the face than other first line NRTIs. Zerit and Videx cause more side effects and are not routinely used in first line treatment.

Three NRTIs are also active against hepatitis B: Viread, Epivir and Emtriva. It’s important to know whether or not you have hepatitis B before starting these HIV meds.

NNRTIs (non-nucleoside reverse transcriptase inhibitors)

In first line regimens, one NNRTI is usually used with two NRTIs. A person would never use two or more NNRTIs together. The Guidelines list Sustiva (also in Atripla) as a *preferred* choice. Many report neurological side effects such as vivid or disturbing dreams, insomnia, difficulty concentrating, mood changes and lack of concentration. People in drug recovery may not want to use Sustiva. Pregnant women (especially during first trimester) and women trying to get pregnant should not take Sustiva due to possible birth defects.

Viramune may be considered instead of Sustiva, mainly for pregnant women and people who wish to save PIs or INIs for later but are concerned about Sustiva’s side effects. Viramune is listed as an *alternative*, due to its risk of serious liver toxicity in people at

higher CD4s. It should not be started in women with >250 CD4s or in men with >400 CD4s. The risk for rash appears to be slightly higher in women than men, and it's more likely to be severe.

Edurant is approved only for people new to treatment and is less potent than Sustiva when started at viral loads above 100,000.

Intelence has not been well studied in first line regimens and should not be used if there are no signs of NNRTI resistance. Rescriptor is rarely used due to its lower potency and difficult dosing.

PROTEASE INHIBITORS (PIs)

This class contains some of the most potent HIV drugs available, and HIV is less likely to become resistant compared to NNRTIs. Most PIs are boosted with a small dose of Norvir. Some doctors prefer to save PIs in case other less complicated regimens fail. However, there aren't enough studies that prove PIs are the best choice.

The Guidelines list Reyataz and Prezista as *preferred* PIs, while Kaletra is *preferred* for pregnant women. Four others are listed as *alternatives*. Aptivus is not used unless a person's HIV is already resistant to other PIs. Crixivan and Viracept are rarely used.

As a class, PIs tend to cause gastrointestinal problems like nausea and diarrhea. They also tend to affect metabolism. Over time, you may see changes in your cholesterol, triglycerides or blood sugar. People with heart disease or diabetes may want to save PIs for their second or third regimens. For pregnant women, PIs may not fully suppress HIV, especially during the third trimester, so the dose may need to be adjusted.

ENTRY INHIBITORS

Selzentry may be used in first line treatment, but in studies it didn't match the potency of Sustiva. The Guidelines state that there is not enough evidence to recommend Selzentry. A *tropism test* must be done before using it. Fuzeon is injected twice a day, which may be challenging for some. It has not been studied as a first line regimen.

INTEGRASE INHIBITORS (INIs)

Isentress is a *preferred* option for first line therapy. We don't yet know enough about its long-term side effects, although it's generally well tolerated and is proving to be a potent HIV drug.

Choosing your first and maybe second regimen

The most powerful and long-lasting activity against HIV comes from a person's first regimen if taken properly. Some experts believe that the best first line strategy is to take the most potent regimen. The longer a person can stay on it without major side effects or drug resistance, the better. Boosted PIs (those taken with a small dose of Norvir) and Sustiva are considered the most potent, though PIs tend to be longer-lasting.

When a person's viral load remains undetectable for at least one year on treatment, it usually remains that way for at least another two years, assuming they take their meds as prescribed. This is true for almost any regimen used.

It's less clear how much the choice of a first regimen will affect how well a second one will work. In most cases, people who start with a PI will likely be able to use Sustiva successfully in the second regimen, and may also be able to use other PIs. Similarly, people who start with Sustiva can usually switch to a PI.

Other experts believe that saving potent and longer lasting meds for second regimens is a better strategy, and that starting treatment with an NNRTI or even an integrase inhibitor is preferable. NNRTIs may also cause fewer long-term changes in cholesterol, triglycerides or body fat compared to PIs, though study data are mixed.

Planning your second regimen ahead of time can be useful. For instance, you may start one regimen, but then find that the drugs don't work as well as you had hoped. You can then proceed to the second with more ease.

MAIN POINTS TO REMEMBER:

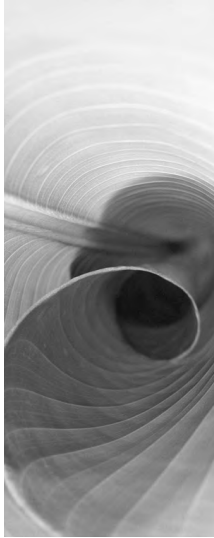
- Some experts believe the most potent regimen should be taken first, while others believe saving the most potent for later is better.
- Less is known about how a first regimen will impact the second.
- Planning ahead for the second regimen may make it easier.

Recommended regimens for first line treatment (updated January 2011)

The Guidelines list “preferred” and “alternative” HIV regimens. Research shows that “preferred” regimens are potent, better tolerated and easier to take. “Alternative” regimens are second choices but may work just as well.

| PREFERRED REGIMENS | | DAILY |
|--------------------|---------------------------------------|---------|
| NNRTI-based: | Atripla (1x/day) | 1 pill |
| PI-based: | Prezista/r + Truvada (all 1x/day) | 4 pills |
| | Reyataz/r + Truvada (all 1x/day) | 3 pills |
| INI-based: | Isentress (2x/day) + Truvada (1x/day) | 3 pills |
| Pregnant women: | Kaletra + Combivir (all 2x/day) | 4 pills |

| ALTERNATIVE REGIMENS | | DAILY |
|----------------------|---|--------------|
| NNRTI-based: | Sustiva (1x/day) + Epzicom (1x/day) or Combivir (2x/day) | 2 or 3 pills |
| | Viramune + Combivir (all 2x/day) | 4 pills |
| PI-based: | Reyataz/r (1x/day) + Epzicom (1x/day) or Combivir (2x/day) | 3 or 4 pills |
| | Lexiva/r (1x or 2x/day) + Truvada or Epzicom or Combivir | 4 to 6 pills |
| | Kaletra/r (1x or 2x/day) + Truvada or Epzicom or Combivir | 5 or 6 pills |
| | Invirase/r (2x/day) + Truvada | 7 pills |



HEALTH:

Your ability to
start and maintain

Keeping up with taking meds

All HIV meds go through extensive research to find the optimal dose to keep HIV under control, without causing unnecessary side effects for most people. They're usually taken once or twice a day, with or without food, because that's the best amount of that drug to suppress HIV. For this and other reasons it's important to *adhere* to your drugs, which means to take every dose as prescribed every day.

One main reason to adhere is to prevent *drug resistance*: a key reason why treatment fails to keep HIV under control. It will eventually force a person to change to another regimen.

Sometimes people don't take their HIV meds when they feel sick from a cold or the flu. Others won't take them because of, or even for fear of, side effects. Sometimes, life just gets too busy to remember to take every dose. If you miss a dose, don't panic: take the next one on time and try to get back on schedule.

In the case of side effects, it's better to try to manage them for awhile rather than miss a dose, take fewer pills or quickly change your regimen. Some HIV meds may cause fewer side effects if you take them at bedtime or with a meal. Other medicines can be used to lessen side effects like nausea. Consult your doctor for help with side effects, especially difficult ones.

Be sure you understand how to take the medicine. Don't be embarrassed to ask your doctor, physician's assistant or pharmacist what the prescription mean. For example, *once a day* doesn't mean whenever you want to take it each day. It means to take it every 24 hours. Don't be afraid to ask others for resources or suggestions to support your adherence.

HELPFUL RESOURCES

Keeping Up with Your Meds www.projectinform.org/publications/adherence/

Side effects

Although most people wonder or worry about side effects, it's impossible to predict who may have them. All drugs, including HIV meds, can cause side effects but not everyone will have them. Some people experience few or no side effects, while others have ones that are manageable. For still others, side effects may be moderate to severe, and can interfere with quality of life. You may also hear a troublesome story from someone else, but that doesn't mean you'll experience those same side effects from the same drug or regimen. HIV drugs affect everyone individually.



Short-term side effects (like headache, fever, nausea) normally appear during the first few weeks of taking a new drug. They often get better or disappear as your body gets used to the meds. Occasionally, side effects reappear due to stress or other infections.

In general, people with better overall health usually experience fewer short-term side effects. If you start later when you're less healthy, you may experience more symptoms.

You and your doctor will keep track of long-term side effects by routinely running blood tests. These can include changes in blood fats or in certain blood proteins (such as ALT, AST, amylase and creatinine) that indicate possible problems with certain organs, including the liver and kidneys. Over time, these changes can progress to other conditions like diabetes or liver disease.

HELPFUL RESOURCES

Dealing with Drug Side Effects www.projectinform.org/publications/sideeffects/

Drug interactions

Drug interactions are possible whenever you take two or more drugs together, whether they're prescriptions, over-the-counter drugs like cold medicine, recreational drugs or even herbal products. Even food can interact with drugs. The more meds you take, such as hormonal birth control or meds for high blood pressure or even erectile dysfunction, the more likely you could experience an interaction. This is also true about taking HIV meds with some herbal products, especially St. John's Wort.

Given the number of drugs used to treat HIV and other conditions that are common among HIV-positive people, possible drug interactions are more likely. Not only does each drug have its own possible side effects, that drug may also increase or decrease the effectiveness of other drugs. Drug interactions are not always considered when making treatment decisions, but they can certainly play a major role in its success.

Thinking ahead about possible interactions can help you avoid unnecessary side effects. Make sure your doctor knows about all the drugs and supplements you take, including over-the-counter products and recreational drugs. Don't forget that your pharmacist can be an invaluable resource. Drug interaction tools are also available online.

MAIN POINTS TO REMEMBER:

- Interactions are possible whenever you take two or more drugs or herbal products.
- Your doctor may have to adjust the dose of some of your meds to avoid or correct drug interactions.
- Planning ahead for possible interactions can help you avoid them.

HELPFUL RESOURCES

Check My Meds www.aidsmeds.com/cmm
HIV Drug Interactions www.hiv-druginteractions.org
Medwatch www.fda.gov/medwatch

Women and HIV treatment

PREGNANCY

One of the greatest successes of HIV treatment is our ability to prevent passing HIV from mother to baby during pregnancy or birth, provided the woman has ongoing access to care and treatment. Several things should be considered when taking HIV meds during pregnancy: ensuring the health of the woman, protecting the baby, when to start, drug choice and drug side effects.



It's important that the doctor you choose is experienced with HIV, women and pregnancy. The US Guidelines recommend that all HIV-positive pregnant women be on treatment, regardless of CD4 count or viral load. Some doctors recommend that women with early-stage HIV disease not start treatment during their first trimester, when the baby's organs are developing. You should weigh these benefits and risks with your doctor.

Some conditions, like diabetes, are common in pregnant women. Some HIV meds may worsen these conditions to some degree. A few HIV meds should not be taken during pregnancy, including Sustiva (due to its risk of birth defects), and Viramune (which may cause severe liver disease in women with CD4s above 250).

If protease inhibitors are used, their dose may need to be increased during the third trimester. It's recommended that Retrovir be included due to its ability to prevent transmission, unless the woman develops severe side effects, or is resistant to it, or is also using Zerit. Videx + Zerit should not be used.

BREAST-FEEDING

HIV is present in breast milk and may be passed from mother to child during breast-feeding. Therefore, the US Guidelines recommend that mothers use formula to feed newborns. This works best when there is easy and ongoing access to formula as well as clean water and refrigeration. HIV meds may be passed through breast milk, although this has not been well studied for all drugs. Women should consult experienced maternity doctors to fully explore their options. Accredited national or local breast milk banks may also be an option and may meet the infant's need for breast milk.



CONTRACEPTIVES

Many HIV meds, mostly protease inhibitors and NNRTIs, can interact with hormonal birth control pills (those that contain *ethinyl estradiol*, *norethindrone*). These interactions can alter the potency of the birth control pill or HIV meds. In this case, women may consider other HIV meds or use another form of birth control instead of, or in addition to, the pill. Less is known about how HIV meds interact with the *transdermal patch* or *vaginal ring*.

HELPFUL RESOURCES

CDC Perinatal Guidelines www.aidsinfo.nih.gov/guidelines

Perinatal HIV Hotline 888-448-8765

Special Issues for Women www.aidsmeds.com/articles/Women_7563.shtml

Pregnancy and HIV www.aidsmeds.com/articles/Pregnancy_4900.shtml

HIV and Breastfeeding www.thebody.com/content/art13590.html

National Milk Bank www.nationalmilkbank.org

Human Milk Banking Association www.hmbana.org

Power of the mind

The power of the mind in health and healing can really make a difference over time. Nearly two out of three people in clinical studies who take a placebo (a sugar pill with no medicinal value) get some of the same benefits as people taking a real drug. This is because they believe that what they're taking is good for them. This can also apply to HIV-related medications and alternative therapies.

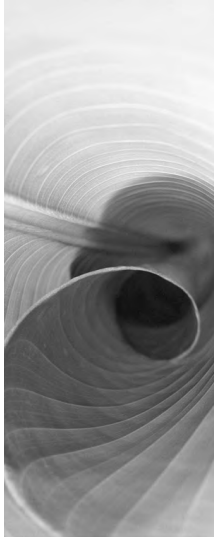


If you believe that a particular medicine is “poison,” chances are you’ll experience side effects and won’t do as well on it. On the other hand, if you believe that something you’re taking is good for you, then you’ll more likely have an overall better experience with the treatment and perhaps experience fewer side effects.

In exploring your beliefs about a medicine, you might find you’ve come to a conclusion based on fears or rumors. Grounding yourself in facts, rather than fears, is critical to making good decisions. Personal experience and knowledge about a given medicine is far better information to inform your decisions than fears or conjecture.

MAIN POINTS TO REMEMBER:

- What you think or believe about something, like a certain medicine, can affect how well you do on it.
- Learning about a medicine ahead of time may help ease your fears or concerns.



SELF-ADVOCACY:

Getting ready to start
HIV treatment

Is your doctor experienced in treating HIV?

You will need to find a doctor who's able and willing to treat HIV, ideally one who already has experience with HIV and whose style works for you. Depending on how and where you get health care, you may not have many choices.

Experienced HIV doctors, due to the number of patients they see, usually keep up with recent developments in treating HIV. They also have a better sense of preventive health care. If you can, it's also important to find other doctors like gynecologists, eye doctors and dentists who have HIV experience.

Doctors with less or no HIV experience may need to consult resources that can help them provide the best medical care for you. This will take time, but resources are available that can help you and your doctor make informed decisions.

The **WarmLine** (National HIV Telephone Consultation Service) is staffed by experienced doctors and provides expert clinical advice to other medical professionals. It's available Monday–Friday, 8am–8pm, Eastern Time. (See number below.)

Many areas of the country have regional **AIDS Education Training Centers** that provide education programs for health providers who treat people with HIV.

HELPFUL RESOURCES

Guidelines for Treating HIV in Adults www.aidsinfo.nih.gov/guidelines/

WarmLine 800-933-3413 (for doctors only)

www.nccc.ucsf.edu/about_nccc/warmline/

AIDS Education Training Centers www.aids-ed.org

Clinical Care Options www.clinicaloptions.com

GLMA's Find a Provider www.glma.org, click **RESOURCES >> PATIENT**

HIVMA's Find a Provider www.hivma.org, click **DIRECTORIES**

AAHIVM's Find a Provider www.aahivm.org, click **MEMBERS**

Association of Nurses in AIDS Care www.anacnet.org

Important questions

FOR YOUR DOCTOR

- What regimen(s) do you recommend and why? Is one better than another?
- What should be my next regimen if the first one doesn't work?
- How many pills will I take? How often? With or without food?
- What are the possible side effects of the drugs I would take?
- What side effects are more likely to get better over time? Which ones are serious? Which ones should I tell you about ASAP?
- When should I let you know if I think something is wrong?
- What do you mean when you say I should adhere to my drug regimen?
- Wonder might happen if I miss a dose or two?

FOR OTHERS

- When did you start treatment, and why?
- What regimen did you take?
- What problems did you encounter with that regimen?
- If you had any side effects, what were they and how did you handle them?
- How did starting treatment impact your life? Were you prepared enough?
- Have you told anyone about your status and taking meds? How did that go?
- How do you keep up with your regimen?

Managing your quality of life

A lot of attention is put into making decisions about when to start and what to choose. But it's also important to consider your future over the next few years or even decades.

STABLE ACCESS TO DRUGS

It's not uncommon for people to run out of one or more of their meds on occasion, but having a steady supply should be a priority. It can help you live your life more fully rather than waiting until the last moment to get a prescription filled. Keeping a steady supply requires you to work closely with your doctor, pharmacist and possibly insurance administrators.

Certainly, the best way to avoid emergencies is by planning ahead for weekends, vacations, moves or other times when your regular routine is disrupted. But even with good planning, meds get lost or people just forget to take them. What will you do to make sure you get your next dose? Auto-refills or mail order refills can help with this.

First, work with your doctor to establish about a week's overlap so you always have seven days (or more) of backup in case of emergency. If you go on an extended vacation, make sure you have enough meds for the time before you leave, when you're away and the first week after you get back. Refresh your emergency supply to avoid expired pill.

It's also important to consider people you would call in case of an emergency, and keep those numbers with you. Who would you call on a weekday or weekend? Would your insurance cover a visit to an ER to get meds?

If you rely upon a public program, make sure you know when you need to re-apply and if you have out-of-pocket costs. Be sure to keep up with enrollment requirements of your insurance and any premiums or out-of-pocket expenses. Make sure you read, act on and file papers sent to you by these programs.

SUPPORT NETWORK

Having people around you — friends, family, support group members, neighbors or medical providers — helps support your emotional and practical needs. Friends could remind you to take your meds. If you know other HIV-positive people, you can help each other by talking about how to handle certain problems related to HIV.

EVALUATE YOUR REGIMEN

Because your life and health change over time, your regimen may need to as well. What worked when you started treatment may not be the best fit a few years later. So it's important to revisit your treatment from time to time and ask yourself how you're doing. Does it still fit your medical needs and lifestyle? Do you want to try something else? In the end, you may not need to change anything, but at least you considered it as part of maintaining your health and quality of life.

KEEP A DIARY

Keeping a diary is not for everyone, but it may be useful to remember details that might help you manage certain aspects of HIV treatment or help you explain certain issues to your doctor. You may find different connections; for example, between certain types of stress you experience and side effects. Include whatever is important to you: when you took your meds, reason for missed doses, how you felt, etc.

Checklist for getting started

- I understand the health risks of a CD4 count
 - below 200; below 350; below 500; above 500.
- I've been able to find a doctor experienced in treating HIV.
- Since I haven't been able to find an experienced doctor, I've discussed with my current doctor ways to improve our knowledge around treating HIV.
- I will ask how to properly take my medicines.
- I know what my first regimen will be and why I want to use it.
- My doctor and I have planned ahead in case my first regimen doesn't work out.
- I understand how my doctor and I will check to see if my regimen is working.
- I understand the need to take my meds on schedule every day.
- I know what situations might make me miss a dose.
- I know what side effects may give me the most problems, like nausea or diarrhea, and which likely get better over time.
- I understand that long-term side effects are possible and that some of them are not known yet, as with the newest drugs.
- I'm aware of what I can do to help avoid or lessen side effects.
- I'm aware of what I can do to help avoid or reduce resistance.
- If I want privacy when taking my meds, I've thought about how to ensure that.
- I have dealt with or am dealing with issues that could affect my adherence (housing, substance use, mental health).
- I know how to keep up with the requirements of the programs that cover my care and medications.
- If I have questions and my doctor is not available, I can call _____ or _____.

how to take my medicines

| At this time ... | I take these pills, liquids, or injections ... (put number of pills in parentheses) | And I do these things ... |
|------------------|--|---------------------------|
| ___:___ am/pm | _____ () _____ () _____ () | |
| ___:___ am/pm | _____ () _____ () _____ () | |
| ___:___ am/pm | _____ () _____ () _____ () | |
| ___:___ am/pm | _____ () _____ () _____ () | |
| ___:___ am/pm | _____ () _____ () _____ () | |

EXAMPLES

| | | |
|----------------------|---|---|
| 8 : 30 <u>am</u> /pm | Bactrim _____ (1) _____ () _____ () | Take Bactrim only on Monday, Wednesday, and Friday. Keep an eye out for allergic reactions. |
| 2 : 00 <u>am</u> /pm | Truvada _____ (1) Prezista _____ (2) Norvir _____ (1) | I should take Prezista with food. |



1375 Mission Street
San Francisco, CA 94103

www.projectinform.org/HIVhealth/

To order copies:
email questions@projectinform.org or call at 1-800-822-7422.

To give us feedback: www.projectinform.org/survey/.

To get on our e-mail list: www.projectinform.org/signup/.