ATTAINING HIV HEALTH & WELLNESS:

Considering treatment and your health care

• get informed
• ask questions
• live well
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 of 3)

This booklet helps guide individuals on basic things to do after finding out they’re HIV-positive, with an emphasis on understanding HIV infection, getting into care, and finding a support network.

Considering treatment & your health care
(booklet 2 of 3)

This booklet explores decision making about HIV health, from considering treatment to talking things out with a support network and doctors to thinking more broadly about personal health needs.

What you should know
about when to start & what to use
(booklet 3 of 3)

This booklet focuses on the issues related to taking HIV medications, including deciding when to start and what to use, planning ahead, considering how treatment may affect one’s life, and finding an HIV-experienced doctor.

To order copies of this booklet, email Project Inform at questions@projectinform.org.
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Using this booklet ...

The main focus of this booklet is to get you thinking about your HIV health. For most people, the idea of making decisions together with their doctors is a new experience. Most of us just do as we’re told in regards to taking pills or getting tests done, but HIV disease has greatly changed the way people interact with their doctors. Because treating HIV can be complex at times, your opinion about what you’re willing and ready to do is a critical part of any decision about your health.

Making decisions often means weighing the pros and cons of taking certain medicines, but it also applies to figuring out when to start taking them or considering other aspects of your health such as exercise or nutrition. Whenever you’re faced with a new decision, it’s wise to learn as much as you can about your options ahead of time, giving you more control over your health.

In the following pages, you’ll find different topics that will help you make decisions best suited to you. You’ll notice that we highlight three key areas: knowledge (what can help to know), health (what can help to do), and self-advocacy (how to get what you need). When these three areas work well together, you get better outcomes. We believe that getting informed about HIV, being actively involved in your health, and talking things over with your doctor and support network can result in a longer, healthier life.

You don’t have to read all of this at once — read it at your own pace. 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?

Earlier in the epidemic, HIV-positive people were faced with many more health issues after being diagnosed than what they generally face today. People often had to react quickly rather than plan ahead for their continued good health. This doesn’t mean that certain health issues won’t arise for you, but being forced to deal with a problem occurs less often today. Many now have the time to consider being on treatment before having to start it, as well as time to plan out treatment strategies over the next 10 or 20 years.

In the 80s and 90s, many people had to get into clinical studies to be able to get their HIV meds and health care. Over the years, public care programs as well as private health insurance have greatly improved, which allows more people to find stable medical care. Also, doctors, nurses and other medical professionals are now well experienced with treating HIV, and there are many more resources available to you and your doctor.

Another significant difference is that opportunistic infections (OIs) occur less often today. Cases of PCP and other OIs are seen mostly in those not aware of their HIV status who show up in emergency rooms for care. But now that you know, you and your doctor will monitor your health well before these infections would normally appear.

Today you have more treatment choices. You may still have to overcome hurdles with health care coverage, but you likely have more time on your side. This can allow you to get used to your diagnosis, explore your options, and make room to more thoughtfully decide what’s best for you. Today’s treatments will enable you and your doctor to tailor your new regimen for you. If you need to change treatment, there are safer options today than 10 years ago.
KNOWLEDGE:

Learning how to treat HIV disease
Why take HIV medications?

The relationship between HIV levels and risk of disease progression is complicated, and it varies from person to person. Although some people can maintain good health for many years without being on treatment, it’s likely that the immune system will not be able to fully suppress HIV on its own over time, especially during early infection. An aggressive battle is waged daily between HIV and the immune system. Without treatment, HIV will eventually weaken the immune system.

Taking HIV meds can help the immune system better control the infection for a much longer period of time. The goals for treating HIV are to:

• Prolong life and improve the quality of life;
• Help the immune system better control HIV;
• Suppress viral load as low as possible for as long as possible;
• Reduce the development of resistance; and
• Help prevent transmission of HIV to others.

PROLONGING LIFE

Being on treatment can greatly extend a person’s life, but it should not interfere with your quality of life, if at all possible. The regimen should be easy enough to use so every dose can be taken as prescribed. For most people, it’s possible to find a regimen that works with minimal side effects, taking into account possible drug interactions. If you cannot tolerate a drug or the regimen isn’t working for you, it’s possible there are other options to switch to.
HELPING THE IMMUNE SYSTEM
Treatment helps the immune system slow and stop HIV replication. One outcome of this is a higher CD4 count, which shows your body is becoming more adept at keeping HIV levels as low as possible. Some people may find a rapid rise in their CD4s after starting, while others the increase may take more time.

SUPPRESSING VIRAL LOAD
Reducing viral load typically leads to a stronger immune response and better health. The goal is to keep it as low as possible for as long as possible, preferably undetectable (below 50 copies). People with high viral loads before starting may find their HIV levels drop slowly (perhaps six or more months), while healthier people may see faster responses (perhaps a few months). The minimum change that shows treatment is working is 90% less viral load, or a 1 log difference.

REDUCING RESISTANCE
One main concern with HIV treatment is drug resistance. This happens when HIV is able to change enough to resist the drugs. When HIV is fully suppressed, it’s less likely that the virus can become resistant. Therefore, using a potent regimen that fully suppresses HIV is one main goal for treatment. Taking every dose as prescribed, staying undetectable, and getting resistance tests done can help prevent resistance.
Starting treatment vs. not starting treatment

The most difficult issue you’ll probably face is when to start HIV meds. If taking HIV meds was as easy as taking a multi-vitamin every day — without side effects or even risks from long-term use — then deciding to start would be much easier.

There’s a lot riding on this decision, and there’s a lot to contemplate before you decide. So it’s natural to feel anxious or overwhelmed when confronted with the issue. Nevertheless, hundreds of thousands of people have been able to figure out how to balance their medical needs along with their personal concerns and still come to reasonable treatment decisions. And you can too.

Given certain aspects of your life, you may even think that you can’t start HIV treatment. Perhaps you don’t have a place to live or you have other health concerns to deal with. Although these can present unique challenges for treating HIV, there are services available for many people to find help.

There’s no one proven “right” time to start HIV meds, although the US Guidelines offer recommendations based on the latest evidence. There are differing opinions about starting treatment early in the course of HIV infection vs. later. While there are times when using treatment is clearly beneficial, when to start remains mostly an individual decision.

For some people, it’s an easy and clear decision. For others, getting more information may help ease your concerns. Still, others may need more time to get used to the idea. It’s important that your treatment plan is one you’re comfortable with
and that you start without feeling pressured but with the knowledge that you can succeed.

However, starting very early may lead to an earlier risk of developing long-term drug side effects and resistance. It’s unclear at this time what all these side effects or resistance will be, but if and when they happen they may not be corrected so easily for some people.

Even if you’re healthy and don’t feel like you want to start HIV meds immediately, it’s still a good idea to learn about your options and begin talking with your doctor about what to do and when to do it. Making those decisions beforehand can diminish some of the fear that can come with starting any kind of treatment for the first time.

OTHER THINGS TO CONSIDER
On average, it can take about 10 years from initial infection before serious symptoms appear, although HIV continues to damage the immune system throughout this time. The one way to control HIV before major symptoms appear is by using effective treatment. More evidence suggests that treating HIV earlier may help reduce immune system damage and inflammation. However, there are risks from taking these meds, which include side effects and drug interactions, adherence issues, resistance (see page 11), covering their cost (see page 26–27) and stigma (see page 18). For more information, read Project Inform’s publication, *HIV, Health & Wellness: What you should know about when to start and what meds to use.*
Resistance testing before starting

Resistance to a drug occurs when HIV changes, or *mutates*, enough so that the drug or regimen no longer fully controls the virus. *Cross resistance* occurs when resistance to one drug causes resistance to other drugs in the same class. Resistance usually occurs when the drugs are not taken as prescribed, consistently, on schedule.

The US Guidelines recommend that people get a *genotype* resistance test before they start HIV treatment as well as before switching to another regimen. Studies show that people who choose treatment while considering their resistance test results have longer lasting responses to their regimens. In order to run a resistance test, you must have a viral load above 1,000. The test cannot be done accurately if your viral load is *undetectable* (below 50 copies).

By taking a resistance test, you and your doctor will have more information to make better treatment decisions. Some studies show that up to 1 out of 6 of all newly infected people in the US have drug-resistant strains of HIV. It’s important to know this before starting treatment.

For instance, if the results show that you have a strain of HIV that is already resistant to one of the NNRTIs, it is almost certainly going to be cross resistant to most other NNRTIs. What this means is that once resistance develops to Sustiva, then other drugs in this class such as Viramune and Rescriptor are less effective, and possibly wholly ineffective. However, there’s generally less cross-resistance among NRTIs and protease inhibitors.

**HELPFUL RESOURCES**

Women and HIV infection

HIV meds have not been studied as much in women as in men. Some questions remain about the doses given to women since women are generally smaller than men, as well as possible female hormonal interactions. However, the recommendations for when and what to start are generally the same for both. Women who are not pregnant, not planning to become pregnant, or not taking oral birth control can follow the same guidelines as men.

Women generally face a higher rate of side effects from HIV meds than men, likely due to differences in their weight and body size. Although side effects may be problematic for women and can persist longer for them than for men, they generally decline over time though probably at a slower rate.

Oral contraceptives can interact with many HIV meds. Therefore, some of the prescriptions may need to be changed to make sure they all work well, and/or other forms of birth control may need to be used.

With careful planning and ongoing care, pregnant women can reasonably expect a safe pregnancy and to give birth to an HIV-negative baby. However, HIV meds have not been well studied in pregnant women even though the US Guidelines recommend that all pregnant women be on treatment to protect them and their unborn babies. Some HIV meds appear to be safer during pregnancy, some can be more problematic, while a few others should not be used at all. Other considerations are delivery and nursing.

When making decisions around these issues, it’s wise to consult HIV-experienced doctors who are also experienced in pregnancy and birth, such as an OB-GYN. For more information, read Project Inform’s publication, *HIV, Health & Wellness: What you should know about when to start and what meds to use*.
Understanding test results

VIRAL LOAD TESTS
Viral load tests are used to check how well treatment is controlling the virus. People who start treatment for the first time usually see their viral loads fall to undetectable levels within the first 12–24 weeks of starting. Several things can influence whether this happens: taking the meds as prescribed, the potency of the regimen, a low or undetectable viral load before starting, and a CD4 count above 200. People with lower CD4s or higher viral loads may take longer to respond.

CD4 COUNTS
One goal of HIV treatment is to stabilize and increase your CD4 count over time, which means your immune system is better able to control HIV. It’s reasonable to expect an increase in CD4s shortly after starting treatment, perhaps an extra 100 CD4s within the first year or year-and-a-half. However, the actual increase will vary from person to person. If you start treatment with a lower CD4 (below 200), then it usually takes more time to see higher counts. With ongoing treatment, some people continue to see consistently small increases over time while others may have none.

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<thead>
<tr>
<th>CD4 RANGE</th>
<th>WHAT IT GENERALLY MEANS</th>
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<tr>
<td>Below 200</td>
<td>Should be on treatment. Constitutes an AIDS diagnosis.</td>
</tr>
<tr>
<td>200–350</td>
<td>Should be on treatment. Some disease symptoms likely.</td>
</tr>
<tr>
<td>350–500</td>
<td>Recommend treatment.* Symptoms less likely, but possible.</td>
</tr>
<tr>
<td>Above 500</td>
<td>“Normal” range. Could be on treatment.* Symptoms less likely.</td>
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*From US Guidelines for treating HIV. For more information, read Project Inform’s publication, HIV, Health & Wellness: What you should know about when to start and what meds to use.

CD4 PERCENTAGE
Although looking at the CD4 count is important and is one of the main test results that you and your doctor will use, the CD4 percentage is equally as important. This shows the percent of all
white blood cells that are CD4s, which in healthy HIV-negative people averages around 40%. In people living with HIV, it averages about 25%. This marker tends to change less often between test results than the CD4 count and may be more reliable. A decreasing CD4 percentage over time shows a damaged immune system, and one that falls below 14% is an AIDS diagnosis.

**CD8 COUNTS**

CD8 counts are not normally used to make treatment decisions, but they can provide useful information. CD8 cells seek out and destroy other immune cells that are infected with HIV. A CD8 count of 150–1,000 is the average range for healthy HIV-negative people, but people living with HIV normally have even higher CD8s perhaps because more are needed to kill infected cells.

**CD4 / CD8 RATIOS**

Besides the absolute numbers of CD4s and CD8s, another important test is the CD4/CD8 ratio. The normal CD4/CD8 ratio for HIV-positive people ranges from 0.9–6.0. An increasing ratio over time indicates immune recovery and that treatment is working.

**OTHER TESTS**

You’ll get other regular blood tests done like a complete blood count and chemical panel. Both provide a good picture of other aspects of your general health. Abnormal levels may point to certain conditions like anemia or illnesses such as a bacterial infection. They also measure various chemicals in your blood that may point to drug side effects or possible problems with your liver or kidney. It’s important that you review and understand what these test results mean for you and your risk for other conditions.

**HELPFUL RESOURCES**

- Understanding Your Lab Results  [www.thebody.com/content/art14477.html](www.thebody.com/content/art14477.html)
The classes of HIV meds

When you start, the regimen will likely include three drugs from two different classes. Research shows that using drugs in this way is the most potent way to suppress HIV. Different classes of drugs work against HIV in a different place of its life cycle. Suppressing HIV in two places instead of just one will provide you with better and longer-lasting health outcomes.

Five classes of HIV drugs are approved:
- NRTIs/NtRTIs (nucleoside/nucleotide reverse transcriptase inhibitors)
- NNRTIs (non-nucleoside reverse transcriptase inhibitors)
- PIs (protease inhibitors)
- Entry inhibitors
- INIs (integrase inhibitors)

People going on treatment for the first time will likely start with 2 NRTIs and one NNRTI, PI or INI. (A list of these drugs can be found in the Drug ID Chart on page 14.) Some of these drugs have been combined into one pill, so that depending on the regimen you may be able to take just one pill a day. Other easy-to-take regimens are also available.
## Drug ID chart

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

### NRTIs
*(NUCLEOSIDE 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)

### NNRTIs
*(NON-NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITORS)*
- Intellence (etravirine, 2008)
- Rescriptor (delavirdine, 1997)
- Sustiva (EFV, efavirenz, 1998)
- Viramune (nevirapine, 1996)

### ENTRY INHIBITORS
- Fuzeon (T20, enfuvirtide, 2003)
- Selzentry (maraviroc, 2007)

### INTEGRASE INHIBITORS
- Isentress (raltegravir, 2007)

### PIs
*(PROTEASE INHIBITORS)*
- Aptivus (tipranavir, 2005)
- Crixivan (indinavir, 1996)
- Invirase (saquinavir, 2003)
- Kaletra (lopinavir/r, 2000)
- Lexiva (fosamprenavir, 2003)
- Norvir (ritonavir, 1996)
- Prezista (darunavir, 2006)
- Reyataz (atazanavir, 2003)
- Viracept (nelfinavir, 1997)

### 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](http://www.aidsmeds.com/list.shtml)
Stay informed!

Getting informed and learning about HIV and your options may seem overwhelming at first. There’s a lot of information to sort through and sometimes it can seem like it’s written in a foreign language. But it’s something that you can learn to read. Keeping up with the latest information can help you make better treatment decisions, and many people feel empowered by it.

Hundreds of studies are done every year on some aspect of HIV disease. Some of the results can lead scientists to new discoveries about how HIV causes disease. Or, they may even change the way we treat HIV disease, like how to dose a drug more safely or how to use a more sensitive blood test.

You may want to consider reading HIV study results at some point. There can be a lot to sort through, so it may take some effort. Below is a list of resources for finding results from clinical studies.

**HELPFUL RESOURCES**

**COMMUNITY AND GOVERNMENT RESOURCES**

- NATAP  [www.natap.org](http://www.natap.org)
- AIDS Meds  [www.aidsmeds.com](http://www.aidsmeds.com)
- The Body  [www.thebody.com](http://www.thebody.com)
- AIDS Map  [www.aidsmap.com](http://www.aidsmap.com)
- HIV and Hepatitis  [www.hivandhepatitis.com](http://www.hivandhepatitis.com)
- Clinical Trials Network  [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- AIDS.gov  [www.aids.gov](http://www.aids.gov)

**HIV-RELATED CONFERENCES**

- CROI  [www.retroconference.org](http://www.retroconference.org)
- ICAAC  [www.icaac.org](http://www.icaac.org)
HEALTH:
Consider how HIV treatment fits into your life
Are you ready?

It can be hard to take medicines and stay on them when you’re feeling well. People usually take them when they feel sick. Studies show that even doctors have a hard time staying on a short course of medication, such as antibiotics. But HIV meds are taken every day ... whether you feel good or feel bad.

How do you feel about taking pills every day, perhaps for life? It’s difficult to fully comprehend the needs of “lifelong” treatment, but once you start HIV meds you will need to stay on them. Have you had to take other medicines or vitamins long-term? How about family or friends? What are their experiences?

Do you feel confident that starting now is right for you? What makes you feel this way? Or, are you anxious or worried? Have you talked with your doctor about your concerns? Have you seriously considered all the risks vs. the benefits?

You may want to avoid starting meds before major life experiences like going on vacation, moving or starting a new job, since adjusting to several changes at once can be harder. What support and flexibility do you have with commitments like taking care of children or volunteering? How do you plan to carry your meds?

In the end, you are the expert on when you can start in a way that helps ensure your quality of life. It’s generally better to not start at all rather than to start and stop. Your willingness to stay on your regimen over the long-term as well as getting informed up front on all your options can influence how well you do.

STIGMA

For many, privacy is an important consideration when taking HIV medicines. Taking medications on time every day or going to regular doctor visits may raise suspicions from others in your life. Disapproval or discrimination from others can keep some people from taking care of themselves. When possible, discreetly telling people who support you can help you stay healthier.
Managing co-infections and other conditions

All HIV-positive people should get a full physical and medical history done after their diagnosis, including screening for current infections or conditions like hepatitis C or hypertension. Treating both HIV and these other illnesses requires more consideration, so it’s best to know about them as soon as possible.

IRIS (Immune Reconstitution Inflammatory Syndrome)
IRIS is a serious condition that can happen shortly after starting HIV treatment. The immune system can respond aggressively to other infections, like TB or cryptococcal meningitis, that may or may not have been known before starting HIV meds. Symptoms may include fever, swollen lymph nodes, lesions, rashes, changes in breathing, pneumonia, hepatitis, abscesses and eye redness. It’s wise to report these symptoms to your doctor as soon as possible.

HEPATITIS C
There is no vaccine to prevent hepatitis C, and 1 out of 4 people with HIV are co-infected with it. Many do not know they’re infected; therefore, it’s important to be screened. The virus most often is passed through blood, usually when sharing needles. However, newer evidence shows it’s can be passed through sex, most likely when blood is present in sexual fluids. HIV infection can make hepatitis C disease worse, and certain HCV strains are harder to treat. It’s unclear whether hepatitis C makes HIV worse. Current treatment can be very difficult to tolerate and is successful in about 1 out of 3 people. However, newer treatments are in study and a few are soon to be approved and show a much higher cure rate. Seek experienced doctors when making decisions about treating hepatitis C and HIV.
HEPATITIS B
If you haven’t had hepatitis B, the HBV vaccine will prevent infection in most people. If you do have hepatitis B, about 1 out of 4 people may develop chronic disease, though we don’t fully understand how hepatitis B and HIV interact. When treating hepatitis B disease is needed, the federal HIV Guidelines recommend starting HIV treatment. Three HIV meds have some activity against hepatitis B: Viread (also in Truvada, Atripla), Emtriva (also in Truvada, Atripla), and Epivir (also in Combivir, Trizivir). One of these should be used as part of the HIV regimen.

DIABETES
Diabetes is common in the general public. Many people don’t know their risk for it and go undiagnosed for it. Women can experience diabetes during pregnancy as well, and there’s a higher rate of diabetes in HIV-positive people. It’s important to be screened for it before starting HIV treatment. Some HIV meds, such as protease inhibitors, can contribute to the condition to some degree. Managing both diabetes and HIV disease is possible, given the various medicines used for both. More attention may need to be paid to interactions between diabetes and HIV drugs.

ORGAN DISEASE
HIV infection can contribute to disease in the liver, kidney, heart and other organs. The level of disease depends upon several factors, such as genetics, your general health, other infections and lifestyle issues. HIV meds can also contribute to organ disease, so it’s important to know what risks you have before starting your first regimen. For instance, if you have kidney disease, avoiding Viread and Truvada may be appropriate. If you have heart disease, you may want to avoid Ziagen. Lifestyle changes could be made as well, such as eating healthfully, exercising and stopping smoking.
BONE LOSS
New evidence shows that the general public has lower than normal levels of bone mass and vitamin D. For people with HIV, the rate of loss is higher perhaps due to HIV itself, although there’s not a higher rate of fractures or breaks. Starting on HIV meds may cause some bone loss. Although some studies show that this loss levels out within a year or two, other studies show continual loss during long-term treatment. NRTIs and PIs may contribute some amount to bone loss. Getting screened to see if you’re at risk is important, along with vitamin D supplements or prescriptions for bone loss when necessary.

HELPFUL RESOURCES

IRIS  www.projectinform.org/info/iris/
Towards a Healthy Liver  www.projectinform.org/info/liver/
HCV and Gay Men  www.projectinform.org/info/hepc/gaymen.shtml
Risks to Your Liver  www.aidsmeds.com/articles/Hepatotoxicity_7546.shtml
HIV and Liver Health  www.poz.com/factsheets/fs_2009_07_liver.pdf
Risks to Your Heart  www.aidsmeds.com/articles/Hyperlipidemia_7522.shtml
HIV and Heart Health  www.poz.com/factsheets/fs_2009_07_heart.pdf
Risks to Your Kidneys  www.aidsmeds.com/articles/kidneys_12385.shtml
Tips for Healthy Lungs  www.aidsmeds.com/articles/lungs_16905.shtml
Bone Health and HIV Disease  www.projectinform.org/info/bone/
Risks to Your Bones  www.aidsmeds.com/articles/Bones_7548.shtml
Getting certain vaccines

Early in your HIV care, your doctor should talk to you about which vaccines would be appropriate for you. This is an important step to take since some infections can lead to diseases, such as hepatitis A or B. It’s better to prevent these diseases in the first place than having to treat them along with HIV.

Your doctor should fully investigate your medical history and run blood tests to check if you’ve already been exposed to certain infections. Some vaccines may only need to be taken once, but others may need a booster shot. In addition, talking to your doctor about your lifestyle or concerns for disease can lead to better decisions.

In general, HIV-positive people should not get what are called whole killed or live attenuated vaccines. These could possibly cause serious problems for HIV-positive people because they’re made from living organisms. One example is the seasonal nasal vaccine for the flu, called FluMist. HIV-positive people should not use this vaccine.

Recommended vaccines are ones called subunit or conjugated vaccines. They are made only from parts of a virus or bacterium and can’t cause disease. To make sure, you can ask the question before getting vaccinated: Is this the right vaccine for me since I’m HIV-positive?

Vaccines work best at higher CD4s, usually above 200, so it may be better to wait until you’re healthy enough so that the vaccines have a better chance to protect you. Also, if you get vaccinated and then get blood work done soon afterwards, the vaccine may cause your viral load and/or CD4 count to fluctuate. This should return to normal by your next regular blood draw.

On the next page are the US Recommended Immunizations for HIV-Positive Adults, updated January 2009.
Vaccines recommended for HIV+ people

**RECOMMENDED FOR ALL HIV-POSITIVE ADULTS**

**Hepatitis B (HBV), 3 shots over 6 mos.**
Recommended unless there’s evidence of immunity or active hepatitis. Checking HBV antibody levels with a blood test should be done after completing the series of shots. More shots may be needed if antibody levels are too low.

**Twinrix combo HAV/HBV (see below)**

**Influenza (flu), 1 shot, each year**
Only injectable flu vaccine should be given to people with HIV. The nasal spray vaccine (FluMist) should not be used.

**Pneumonia, (polysaccharide pneumococcal, PPSV), 1 or 2 shots**
Should be given soon after HIV diagnosis, unless taken within past 5 years. If CD4s are below 200 when vaccine is given, another should be given after CD4 count goes above 200. Repeat once after 5 years.

**Tetanus (lockjaw) & diphtheria (Td), 1 shot**
Given every 10 years.

**Tetanus, diphtheria & pertussis, 1 shot**
Recommended for people 64 years and younger, given in place of next Td booster. Can be given as soon as 2 years after last Td for health care workers and persons in close contact with babies under 12 months.

**HAV/HBV (Twinrix), 3 or 4 shots over 1 yr.**
Can be used in those who need both HAV and HBV immunization.

**Bacterial pneumonia (Haemophilus influenzae B), 1 shot**
Adults with HIV and their health providers should discuss whether this vaccine is needed.

**Human papillomavirus (HPV), 3 shots over 6 months**
Recommended for females ages 9–26, but not recommended during pregnancy. Optional for boys and men up to 26 years old.

**Measles, mumps and rubella (MMR), 1 or 2 shots**
People born before 1957 do not need to take this vaccine. HIV-positive adults with CD4s below 200, history of AIDS-defining illness, or clinical symptoms of HIV should not get the MMR vaccine. Each part can be given separately if needed.

**Bacterial meningitis, 1 shot**
Recommended for college students, military recruits, people without a spleen, and people traveling to certain parts of the world.

**Chickenpox (Varicella), 2 shots over 4–8 weeks**
People born before 1980 do not need to take this. Recommended unless there’s evidence of immunity or CD4 count is below 200. Not recommended during pregnancy.

**RECOMMENDED FOR SOME HIV-POSITIVE ADULTS**

**Hepatitis A (HAV), 2 shots, 1/1.5 years**
Recommended for health providers, men who have sex with men, hemophiliacs, people who inject drugs or with chronic liver disease or traveling to certain parts of the world.

**NOT RECOMMENDED FOR HIV-POSITIVE ADULTS**

**Anthrax, Smallpox, Shingles (Zoster),**
except adults 60 years of age and older
Herbs, recreational drugs and HIV medicines

Using HIV medicines with herbal products, supplements and recreational drugs can sometimes cause serious interactions. It’s wise to understand this issue to help you better manage your health. Because these interactions are not routinely studied, much of what we know comes from people reporting them to their doctors or in emergency rooms.

Of the many complementary therapies available, several interact with a few prescription drugs to some degree: echinacea, goldenseal, ginseng, vitamin E and fish oil. In some cases, there’s a known interaction and in others it’s suspected. How these examples apply to HIV meds are not fully known.

A few supplements are known to affect the blood levels of HIV meds, which may cause your regimen not to work as well as it could. For example, St. John’s Wort, garlic supplements and perhaps milk thistle are generally discouraged. You may want to speak to your doctor, pharmacist or trained nutritionist who can provide more information to avoid unnecessary interactions.

Using recreational drugs such as ecstasy, ketamine and others with HIV meds can cause severe reactions, such as drug-induced hepatitis, heart attacks, paranoia and death. [For example, using erectile dysfunction drugs (Viagra, Cialis, Levitra) with protease inhibitors can cause severe low blood pressure and death.] For more information, consult the resources below.

HELPFUL RESOURCES

Herbs, Recreational Drugs and HIV meds
www.projectinform.org/info/herbs/

Recreational Drugs and HIV Antiretrovirals
www.projectinform.org/info/streetdrugs/streetdrugs.pdf

Consumer Lab www.consumerlab.com
SELF-ADVOCACY:
Talking things out
Getting your health care covered

In the US, nearly 4 out of 5 people with HIV rely on public programs for their health care. And although you may never need to file for disability, it may be easier to understand your options if you think in terms of pre- and post-disability. Disability is a formal claim that must be made with your doctor and approved by the Social Security Administration. When finding programs you’re eligible for, it’s important to use local resources such as a benefits counselor, case manager, social worker or attorney as programs differ greatly around the US.

IF YOU HAVEN’T FILE FOR DISABILITY …

GROUP INSURANCE THROUGH YOUR EMPLOYER
If your employer provides you health insurance, the insurance company must cover you even if you have a pre-existing condition like HIV. There are three general types of plans: fee-for-service, preferred provider organizations (PPOs), and health maintenance organizations (HMOs). Plans vary in the services they offer, their fees and your choice of doctors. Check with your plan for HIV-experienced doctors.

INDIVIDUAL PRIVATE INSURANCE
Individual plans are an option, but few people can purchase them due to high cost and restrictions on pre-existing conditions. If you had coverage before your diagnosis, you’re likely to get most if not everything you need covered. Your out-of-pocket expenses may be high.

HIGH RISK INSURANCE POOL
Thirty-six states run this program for those who can’t get insurance due to pre-existing conditions. In addition, the federal government has set up a new high risk insurance pool program which will operate in all states and DC until 2014 when health care reform is more fully enacted.

RYAN WHITE PROGRAM
The federal Ryan White Program funds a broad array of HIV services in states and localities, depending on their unique needs. It is intended to help uninsured or underinsured people. If you have insurance, you may be able to get help with premiums or other out-of-pocket costs. If you don’t have insurance, your state may help you purchase it. You may also get free or very low cost care through HIV clinics and the AIDS Drug Assistance Program (ADAP). Ryan White may also fund dental and vision care. Check at the state or local level to see if a Ryan White program can help you.
Getting your health care covered

IF YOU HAVE AN APPROVED DISABILITY CLAIM …

COBRA
If you leave work and had insurance, you will be offered a continuation policy called COBRA. This sometimes expensive coverage is meant to sustain you until you’re eligible for Medicare. Check with your local ASO or state AIDS office for programs to help you with out-of-pocket costs.

MEDICAID
Most people with HIV enter Medicaid through its disability category, although some women with children can qualify through a different program. Nearly all states require a disability claim, income and assets to qualify. Six offer Medicaid to all childless adults (AZ, DE, HI, MA, NY and VT), while another 18 offer some benefits. States vary greatly in what they offer.

MEDICARE
If you have worked, you’ll likely qualify for Medicare. However, you must wait 29 months after your disability claim, during which you may be able to get your health care covered through COBRA, Ryan White, ADAP or Medicaid.

VETERANS ADMINISTRATION (VA)
If you are a veteran, you’re eligible for care through the VA system, which varies in its ability to provide HIV care, and is found only in certain areas. As a veteran, you can access Ryan White programs, but if your VA facility is accessible and offers quality HIV care, it’s a good option.

OTHER POSSIBLE SOURCES OF HELP

PATIENT ASSISTANCE PROGRAMS (PAPS)
PAPs are run by HIV drug makers to supply people with meds with no other access. These are not ideal for long-term coverage but have helped many in the short-term or as an emergency. They differ widely in eligibility.

HELPFUL RESOURCES

Getting Your Health Care Covered  www.projectinform.org/info/hc/
Federal resource on health care  www.healthcare.gov
High Risk Insurance Pools  www.projectinform.org/info/highrisk/
List of PAPs for HIV meds  www.atdn.org/access/pa.html
Medicare  www.medicare.gov
Social Security Administration  www.socialsecurity.gov
Veterans Administration  www.hiv.va.gov
Be flexible with your decision making

As you begin making decisions about your health and how to treat HIV, understand that your decisions may need to change over time. What you decided to do two years ago may not apply today. Treatment information changes over time, your health may be different, and your feelings and opinions can also change, so it’s important to keep those things in mind.

Giving yourself permission to change your mind can help you be more responsive to new developments in your health. An unexpected OI may appear that causes you to re-evaluate your earlier decision. Or, perhaps you start thinking you want to become pregnant. Being more fluid with your decisions could ease your worries, instead of being rigid with them. The new decision you’re making today, though it may seem contrary to an earlier one, can be appropriate at this time.
Getting opinions from others

Most people have concerns and fears about starting therapies, be they HIV meds or complementary therapies. So learning about other people’s experiences can help inform your own decisions. Talk to friends, or to people in support groups and others who have HIV. Ask them about what kinds of treatments they take. Why did they choose them, how did they benefit from them, and what concerns do they have?

However, exercise some caution when using these experiences as your only source of information. What works for one person may not work for you, as treatment is a very individual decision. The most reliable picture of how you’ll do on a medicine will usually come from well designed clinical studies, because they look at many people taking the same regimen.

Ask your doctor about his or her experience or opinions on treatment regimens or strategies you’re considering. Is there any advice about whether a particular medicine might help you? Has s/he followed other people using the same medicine? Be open with your doctor about the options you’re hearing about and the information reported in sources such as newsletters.

HIV treatment guidelines are not meant to be a cookbook, to be used the same way with everyone. Ask how you might develop a strategy that takes your personal needs and concerns in mind. It’s better to make an informed decision that you feel comfortable with than a hasty one.
Consider other issues in your life

Whether you decide together with your doctor to start or delay treatment, there are things you can do to improve your health and your quality of life with HIV. Many have found that as they adjust to living with HIV, the diagnosis can become a catalyst for seeking out help and taking charge of many aspects of their lives.

It is also true that life challenges and health issues such as “street drug” abuse, alcohol abuse, domestic violence, mental health issues and/or homelessness are very difficult to face on your own. Building a support system of people you can trust can be an essential first step. Social services, support groups, supportive friends and family can be extremely helpful in your pursuit to bring more health into your life.

Clinical studies show that support groups for all types of issues (including HIV) improve an individual’s health. Being able to tell your story to people who understand can be very healing and such groups are rich with advice about how to deal with the issues you face. Although AIDS Service Organizations (ASOs) are more plentiful in most urban areas, no matter where you live you can generally find case managers, social workers or peers who can help connect you with services in your area to help you with the issues you face. For online support, check the Connecting with HIV-positive People section on page 36.
Consider the source

As you learn about HIV medications, be aware of who has written the information you’re reading, as well as any false or misleading claims about them. Consider the source of the information and the reasons why they want to provide it. Project Inform believes the best information comes from unbiased review of clinical studies. People should consider this whenever reading treatment information.

A great deal of this information is available today: from the government, community organizations, support group members, treatment educators, and from the companies who make HIV drugs. There are websites, books and brochures, advertisements and forums. Each has their own reasons for providing their materials to you.

Drug companies that market HIV meds are businesses that may not always provide a balanced view of their products. For example, their advertising may present certain lifestyles that minimize a drug’s possible side effects, which you should be aware of before making a decision to start it.

Community forums and educational materials are often paid for by pharmaceutical companies. This doesn’t mean the information isn’t useful; but you have a right to ask questions about the speaker’s involvement with the company — like whether or not they’re getting paid by the company. Consider how that might influence their ability to provide unbiased information.

HELPFUL RESOURCES

How to Identify AIDS Fraud  www.projectinform.org/info/fraud/
Important questions

FOR YOUR DOCTOR:

☐ Do you start everyone at the same time, or on the same regimen? Why, or why not?

☐ Should I be concerned with the HIV meds interacting with other drugs or herbs that I’m taking?

☐ Should I be concerned about resistance, and how do I make sure I keep ahead of it?

☐ What prescriptions or tests are covered by my insurance (public or private)?

☐ How does my blood work inform my decision to start treatment?

☐ What vaccines do you recommend I get? Why?

☐ What if I’m not ready to start treatment?

☐ Are there any other tests that I should take before starting a regimen?

FOR OTHERS:

☐ Have you started on HIV meds? Why, or why not?

☐ What was important for you to understand to help you make a decision about starting?

☐ When did you know it was the right time to start?

☐ What other ways do you keep yourself healthy?

☐ Do you know of a support group or agency that helps people talk these decisions out?

☐ How do you make sure you take every dose of your meds?

☐ How did your blood work inform your decision to start? Did other things affect your decision?

☐ What HIV treatment information do you rely on? Why?
Checklist for getting started

☐ I am ready to start taking medicines, and I understand the reasons why I want to start.

☐ I am not ready to start taking medicines, and I understand the reasons why I don’t want to start.

☐ My CD4 count is _______.
   The trend is □ stable, □ increasing, □ decreasing.

☐ My viral load is _______.
   The trend is □ stable; □ increasing; □ decreasing.

☐ I understand my goals for taking HIV treatment.

☐ I understand the health risks of a CD4 count
   □ below 200; □ below 350; □ below 500 ; □ above 500.

☐ I understand what signs indicate a weakening immune system.

☐ I have a good understanding of the risks and benefits of starting treatment according to my individual needs.

☐ I have thought about how HIV treatment may impact my life.

☐ I’ve considered the issues around taking HIV meds and oral birth control.

☐ I’ve considered the issues around taking HIV meds and pregnancy.

☐ I’ve considered the issues around taking HIV meds and other conditions, like hepatitis C or bone loss.

☐ I’ve given some thought to how I think taking meds will impact my life.

☐ I have private or public insurance or another way to that will cover the cost of my doctor visits, medicines and blood work.

☐ I know where to go to get other types of support, like mental health or housing services, that will help me stay healthy.

☐ If I have questions and my doctor’s not available,
   I will call __________________ or __________________.
**keeping track of the medicines I take or have taken**

<table>
<thead>
<tr>
<th>Name of medicine or supplement</th>
<th>Start date</th>
<th>Stop date</th>
<th>Side effects I had / reason for stopping / other information</th>
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<tr>
<td><strong>MEDICINES FOR HIV</strong> (prezista, truvada, viread, norvir, etc.)</td>
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| **HIV-RELATED MEDICINES** (bactrim, zithromax, diflucan, etc.) |            |           |                                                             |
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<p>| <strong>PRESCRIPTION BIRTH CONTROL</strong> (ethinyl estradiol, etc.) |            |           |                                                             |
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<th>OTHER PRESCRIPTION MEDICINES</th>
<th>ativan, flonase, zoloft, etc.</th>
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<th>OVER-THE-COUNTER PRODUCTS</th>
<th>tylenol, pepto-bismol, comtrex, citrucel, etc.</th>
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<th>VITAMINS, WEIGHT, AND HERBAL SUPPLEMENTS</th>
<th>milk thistle, st. john’s wort, garlic tablets, etc.</th>
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Online resources that may help

TO FIND RESOURCES FOR HIV CARE

Project Inform
1-800-822-7422, and
www.projectinform.org

Directories for ASOs
www.aidshotline.org (CA only)
www.asofinder.com
www.cdcnpin.org
(click on HIV/AIDS at left)
http://directory.poz.com

Directories for HIV Providers
www.aahivm.org
(click on MEMBERS at top)
www.glma.org
(click on RESOURCES >> FOR PATIENT at top)
www.hivma.org
(click DIRECTORIES at top)

State AIDS Hotlines
www.projectinform.org/hotline/state.shtml

RESOURCES FOR WOMEN

The Well Project
www.thewellproject.org

Three Poz Gals
www.threepozgals.net

WORLD
www.womenhiv.org

Women Alive
www.women-alive.org

CONNECTING WITH HIV-POSITIVE PEOPLE

HIV+ Bulletin Boards
www.thebody.com/cgi-bin/bbs/ubbthreads.php

Strength In Numbers (gay/bi men)
www.sinhq.xbuild.com

Yahoo Support Groups
http://health.groups.yahoo.com/group/hivaidsnetwork/

RESOURCES FOR PEOPLE OF COLOR

Asian/Pacific Islander Wellness Project
www.apiwellness.org

Black AIDS Institute
www.blackaids.org

Latino Commission on AIDS
www.latinoaids.org

National Native American AIDS Prevention Center
www.nnaapc.org
"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/