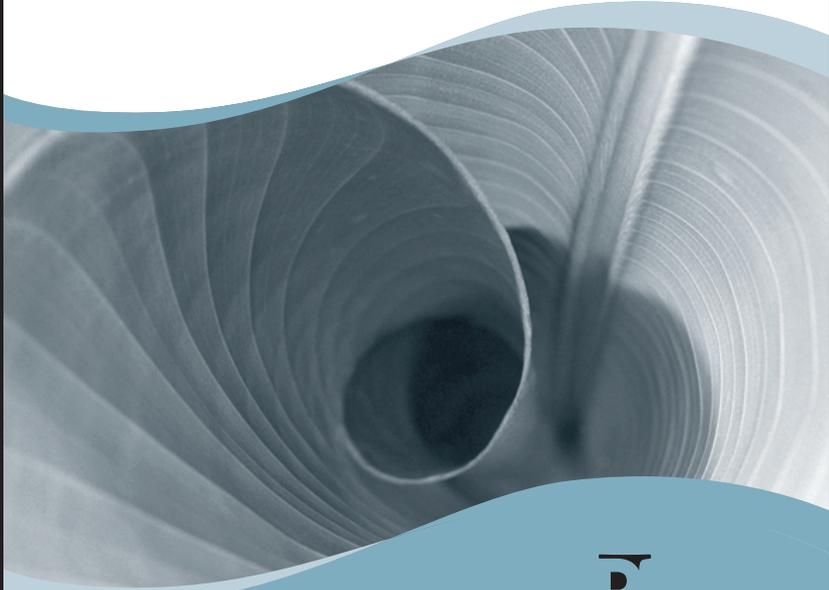


ATTAINING HIV HEALTH & WELLNESS:

# Considering treatment and your health care

- 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.*

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**"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/](http://www.projectinform.org/HIVhealth/)

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

## Using this booklet ...

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The main focus of this booklet is to get you thinking about HIV and your health. For many people, making decisions together with their doctors is a new experience. We sometimes just do as we're told with regard to taking pills or getting tests. But people with HIV have greatly influenced how people interact with their health providers. Because treating HIV can be complex, your ideas about what you're willing and ready to do are a critical part of any health decision.

Making decisions often means weighing the pros and cons of taking certain medicines, but it also involves figuring out when to start them and considering other things 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, which can give you more control over your health.

In these pages, you'll find different topics that will help you make decisions best suited to you. We highlight three key areas: *knowledge* (what's useful to know), *health* (what may be helpful to do), and *self-advocacy* (how to get what you need). When these areas work well together, you get better outcomes. 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. 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

**Attaining HIV Health & Wellness** [www.projectinform.org/HIVhealth/](http://www.projectinform.org/HIVhealth/)

**Just Diagnosed Resource Center** [www.thebody.com/content/art49985.html](http://www.thebody.com/content/art49985.html)

## How is today different from earlier in the epidemic?

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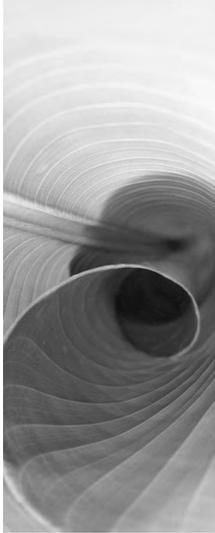
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It used to be that HIV-positive people had to deal with more immediate health issues after being diagnosed than what they generally face today. People often had to react quickly rather than plan ahead for continued good health. This doesn't mean that people diagnosed today won't face certain health issues, but being forced to deal immediately with a problem occurs less often. Many people now have the time to carefully think about being on treatment before starting it, as well as to plan treatment strategies for the next 10 or 20 years.

Over the years, many drugs have been approved, and public health care programs as well as private health insurance have greatly improved their HIV care, allowing more people to find and pay for stable medical care. Also, doctors, nurses and other medical professionals now have more experience treating HIV. There are many more resources available to you and your doctor.

Another difference is that *opportunistic infections* (OIs) occur less often today. Cases of pneumonia and other OIs are now seen mostly in people not aware of their HIV status who go to emergency rooms for care. But once you know you have HIV, you and your doctor can monitor your health well before these infections would normally appear.

Finally, today you have more treatment choices — more than 20 HIV meds. You may still have to overcome hurdles related to health care coverage, but you likely have more time to get used to your diagnosis, explore your options, and more thoughtfully decide what's best. Today's treatments will help you and your doctor to individually tailor the medications you take.



## **KNOWLEDGE:**

Learning how  
to treat HIV disease

## Why take HIV medications?

The relationship between HIV levels and risk of disease progression is complicated and 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 fully suppress HIV on its own over time. The longer you have untreated HIV the more damage it can do to your immune system, making you more susceptible to infections and other problems.

### **PROLONGING LIFE**

Being on HIV treatment can greatly extend a person's life, but it should interfere as little as possible with your quality of life. The regimen should be easy enough to use so you can



take every dose as prescribed. For most people, it's possible to find a regimen that works well with minimal side effects or drug interactions. If you cannot tolerate a drug or the regimen isn't working for you, it's possible to switch to other options.

### **RESTORING AND MAINTAINING IMMUNE FUNCTION**

HIV treatment can greatly slow down HIV replication. One outcome of this is a higher CD4 count, because when less virus is produced fewer CD4s get infected and die. Some people experience a rapid rise in their CD4s after starting treatment, but for others the increase may take more time.

## REDUCING VIRAL LOAD

Reducing viral load makes it easier for the immune system to control HIV, usually leading to better health. The goal is to keep virus levels as low as possible for as long as possible, preferably *undetectable* (below 50 copies). People with high viral load before starting treatment may find their HIV levels drop slowly (perhaps six months or more), while those with less virus may see faster responses. The *minimum* change that shows treatment is working is 90% less viral load, or a *1 log decrease* (for example, 10,000 down to 1,000).

## REDUCING DRUG RESISTANCE

Drug resistance can happen when the virus changes enough so that HIV drugs no longer work. When HIV is fully suppressed, it's less likely that it can become resistant. Therefore, using a potent regimen that fully suppresses HIV is a key goal for treatment. Taking every dose as prescribed and maintaining undetectable viral load can help prevent resistance.

## HELPING TO PREVENT TRANSMISSION

Individuals on potent HIV regimens who maintain undetectable viral loads are less likely to transmit HIV, although active STDs increase the risk. Even with good adherence to an HIV regimen, there's still some risk in transmitting HIV, so it's important to continue engaging in safer sex.

### MAIN POINTS TO REMEMBER:

- HIV treatment prolongs life and improves quality of life.
- HIV treatment helps to keep viral load as low as possible for as long as possible.
- HIV treatment helps keep resistance from developing.
- HIV treatment can restore and maintain immune function.
- HIV treatment helps prevent passing HIV to others.

## Starting treatment vs. waiting to start

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

Given certain aspects of your life, you may think that you can't start HIV treatment. Perhaps you don't have a place to live, struggle with alcohol or drug use, or have other health concerns to deal with. Although such problems can present unique challenges, people in these situations can do well on treatment and services are available to help.

There's a lot riding on this decision and a lot to think about before you decide. So it's natural to feel anxious or overwhelmed. Nevertheless, hundreds of thousands of people have found a way to balance their medical needs with their treatment concerns and quality of life and still make good treatment decisions. And you can too.

There's no one proven “right” time to start HIV meds, although the US Guidelines offer recommendations based on latest research. Experts differ in their opinions about whether to start early in the course of HIV infection or later.

It can take about 10 years from initial infection before serious symptoms appear. But HIV continues to damage the immune system during this time — shown by a falling CD4 count — and HIV may cause inflammation that affects all parts of the body. Early treatment can preserve your immune function and may contribute to better overall health.

But starting treatment very early may mean that long-term side effects and drug resistance will occur sooner. It is not yet known what all these side effects might be. If and

when they happen they may not be corrected so easily for some people. Other possible drawbacks include drug interactions, adherence issues, covering their cost (pp. 26–27), and stigma (p. 16).

While early treatment can be clearly beneficial at times, when to start remains mostly an individual decision. For some people, it's an easy and clear decision. For others, getting more information may be more helpful. Still, others may need more time to get used to the idea. It's important that you're comfortable with your treatment plan and that you start without feeling pressured yet with the knowledge that you can succeed.

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

#### **MAIN POINTS TO REMEMBER:**

- You likely have time to gather information and feel comfortable about treatment before you actually start it.
- Treatment decisions should take into account your personal health and other needs.
- Reading about treatment and talking to others ahead of time can help you feel prepared.
- Many people have made informed decisions. You can too!



# Understanding test results

## VIRAL LOAD TEST

Viral load tests are used to check how well treatment is controlling the virus. The test measures the number of copies of HIV in a small amount of blood. People starting treatment for the first time usually see their viral load fall to an undetectable level within 12–24 weeks. Several factors can influence this, including taking the meds as prescribed and the potency of the regimen. People with lower CD4s or higher viral loads may take longer to respond.

## CD4 CELL COUNT

HIV treatment helps to preserve and increase your CD4 count, which means the immune system is getting better at controlling HIV and other infections. It's reasonable to expect an increase in CD4s after starting treatment, perhaps an extra 100 cells within the first 12–18 months. However, the actual increase will vary from person to person. If you start treatment with a lower CD4 (below 200), it usually takes more time to reach higher counts. Older people and those with hepatitis C may also have smaller gains. With ongoing treatment, many people continue to see small increases over time while others may not experience the same.

CD4 RANGE	WHAT IT GENERALLY MEANS
<b>Below 200</b>	Should be on tx. Indicates an AIDS diagnosis.
<b>200–350</b>	Should be on tx. Some disease symptoms likely.
<b>350–500</b>	Recommend tx.* Symptoms less likely, but possible.
<b>Above 500</b>	“Normal” range. Could be on tx.* Symptoms less likely.

\* From *US Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents*.

## CD4 PERCENTAGE

Although the CD4 count is important — and is one of the main test results that you and your doctor will use — the CD4 percentage is also useful. This shows the proportion of

all white blood cells that are CD4s, which in people living with HIV averages about 25%. This marker tends to change less often between tests than the CD4 count, and it may be more reliable. A decreasing CD4 percentage over time shows a weakening immune system, and one that falls below 14% is an AIDS diagnosis.

### **CD8 CELL COUNT**

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 higher CD8 levels perhaps because more are needed to kill infected cells.

### **CD4 / CD8 RATIO**

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

### **OTHER TESTS**

You should also get other regular blood tests done to monitor your health, including a *complete blood count* and *chemical panel*. Abnormal blood levels may point to certain conditions like anemia or illnesses such as a bacterial infection. Levels of various chemicals in your blood may indicate side effects or suggest possible liver or kidney problems. Review and understand what these test results mean as they can help predict your risk for other conditions.

#### **HELPFUL RESOURCES**

**Blood Work** [www.projectinform.org/publications/bw/](http://www.projectinform.org/publications/bw/)

**Understanding Lab Results** [www.thebody.com/content/art14477.html](http://www.thebody.com/content/art14477.html)

# Resistance testing before starting

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Drug resistance occurs when HIV changes, or *mutates*, enough so that a drug or regimen no longer fully controls the virus. *Cross resistance* occurs when mutations that cause resistance to one drug also reduces the effects of other drugs in the same class. (There are nearly two dozen drugs in five different classes.) Resistance usually occurs when drugs are not taken as prescribed, consistently on schedule.

The US Guidelines recommend that people get a *genotypic* resistance test before they start or change treatment. People who choose treatment guided by resistance test results have longer lasting treatment responses. In order to run a resistance test, you must have a viral load above 1,000. The test cannot be done accurately if viral load is below 50 copies.

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

## MAIN POINTS TO REMEMBER:

- Knowing the results from a resistance test will help you and your doctor make better treatment decisions.
- Get a resistance test done before starting treatment, best done when viral load is above 1,000.
- Some people get HIV that is already resistant in some way. A resistance test can catch this before starting treatment.

### HELPFUL RESOURCES

HIV Drug Resistance Tests [www.projectinform.org/publications/resistance/](http://www.projectinform.org/publications/resistance/)

HIV Drug Resistance Mutations [www.iasusa.org/resistance\\_mutations](http://www.iasusa.org/resistance_mutations)

HIV Drug Resistance Database <http://hivdb.stanford.edu>

# Stay informed!

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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 and study results can help you make better treatment decisions and can make you feel empowered. Others prefer to rely on their experienced doctors and just learn general information. Both can work for you as long you have enough information to participate in health decisions.

Hundreds of studies are done every year on various aspects of HIV disease. Some results lead scientists to new discoveries about HIV; for example, how to combine drugs into more effective regimens or how to use a more sensitive blood test.

As you learn about HIV treatment, be aware of the source of the information you're reading. Be on the lookout for any false or misleading claims. Consider the reasons why this person or group wants to provide it. Project Inform believes the best information comes from unbiased review of clinical studies. People should consider this whenever reading treatment information.

Below is a list of good sources that summarize study findings and interpret what they mean for people living with HIV.

## HELPFUL RESOURCES

### COMMUNITY AND GOVERNMENT RESOURCES

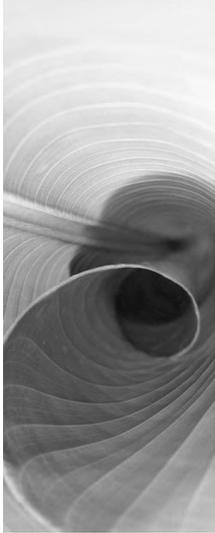
[www.natap.org](http://www.natap.org) [www.aidsmeds.com](http://www.aidsmeds.com) [www.thebody.com](http://www.thebody.com) [www.aidsmap.com](http://www.aidsmap.com)  
[www.hivandhepatitis.com](http://www.hivandhepatitis.com) [www.clinicaltrials.gov](http://www.clinicaltrials.gov) [www.aids.gov](http://www.aids.gov)

### HIV-RELATED CONFERENCES

[www.retroconference.org](http://www.retroconference.org) [www.iasociety.org](http://www.iasociety.org)  
[www.icaac.org](http://www.icaac.org) [www.aids2010.org](http://www.aids2010.org)

**How to Identify AIDS Fraud** [www.projectinform.org/publications/fraud/](http://www.projectinform.org/publications/fraud/)





## HEALTH:

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Consider how  
HIV treatment fits  
into your life

## Are you ready?

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It can be hard to take medicines and stay on them when you're feeling well. It's easier to remember and take them when you 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.

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

Do you feel confident that starting now is right for you? What makes you feel that way? Or, are you anxious or worried? Have you talked to 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 caring for children or volunteering? How will you carry your meds?

In the end, it's generally better to not start until you're ready rather than to start and stop. You're the expert on when you can start in a way that helps ensure your quality of life.

### **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 of some people in your life. Discrimination or disapproval from others can make it challenging to take care of yourself. When possible, discretely telling people who support you may help you stay healthier. Family, friends, a counselor or support groups are options.

# Women and HIV infection

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HIV meds have not been studied as much in women. Some questions remain about the doses given to women. Female hormones may also affect HIV meds. However, the recommendations for when to start and what to choose are generally the same for both sexes. Women who are not pregnant, planning to become pregnant, breast-feeding or taking hormonal birth control can follow the same guidelines as men.

Women generally experience both a higher rate and different types of side effects from HIV meds than men, likely due to differences in their weight and body size. Side effects can persist longer for women than for men, but may decline over time.

Oral contraceptives can interact with some HIV meds. It's not clear whether this actually raises the risk of unintentional pregnancy, but some experts recommend that prescriptions should be changed or other forms of birth control should be used.

With careful planning and ongoing care, pregnant women can expect to have a safe pregnancy and to give birth to an HIV-negative baby. The US Guidelines recommend that all pregnant women be on treatment to protect themselves and their unborn babies, though HIV meds have not been well studied in pregnant women. Some meds appear to be safer, some can be more problematic, and a few others should not be used at all. When making decisions around pregnancy, delivery and nursing, it's wise to consult an HIV-experienced doctor, such as an OB-GYN.



## MAIN POINTS TO REMEMBER:

- When to start and what to use are generally the same for women and men.
- Women generally experience higher rates of side effects than men.
- Consult an HIV-experienced doctor around issues such as birth control pills, pregnancy, delivery and nursing.

## Choosing certain vaccines

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Early in your care, your doctor should talk to you about which vaccines are appropriate. This is an important step since some infections can lead to diseases such as hepatitis A or B or the flu. It's better to prevent these in the first place rather 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 are taken only once and others may need a booster shot, while flu vaccines are taken each year.

In general, HIV-positive people should not get what are called *live attenuated* vaccines. These are made from weakened living organisms and could possibly cause serious problems. One example is the seasonal nasal vaccine for the flu, called FluMist. HIV-positive people should not use this nasal vaccine.

The safest type of vaccines for HIV-positive people are ones called *subunit* or *conjugated* vaccines. These are made only from pieces of a virus or bacterium and therefore can't cause disease. To make sure, you can ask before getting vaccinated: Is this the right vaccine for me since I'm HIV-positive?

Vaccines work best at higher CD4s (above 200), so it may be better to wait until your immune system has recovered so they have a better chance of protecting you. If you get blood work done soon after a vaccine, your viral load and/or CD4 count may fluctuate. They should return to normal by your next blood draw.

### MAIN POINTS TO REMEMBER:

- Talk to your doctor about which vaccines would be best for you and why.
- Vaccines generally provide more protection when the CD4 count is above 200. Sometimes a booster may be needed.
- HIV-positive people should avoid using FluMist and other *live attenuated* vaccines. Always check with your doctor.

# Vaccines recommended for HIV+ people

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From *US Recommended Immunizations for HIV-Positive Adults*, updated January 2009.

## RECOMMENDED FOR ALL HIV-POSITIVE ADULTS

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### 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 (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.

## RECOMMENDED FOR SOME HIV-POSITIVE ADULTS

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### 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.

### 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.

## NOT RECOMMENDED FOR HIV-POSITIVE ADULTS

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**Anthrax, Smallpox, Shingles (*Zoster*),** except adults 60 years of age and older

# Managing co-infections and other conditions

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All HIV-positive people should get a full physical exam and medical history after their diagnosis, including screening for current infections or conditions such as hepatitis C or hypertension. Treating both HIV and other conditions at the same time 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, especially at low CD4s. As the immune system begins to recover, it can respond aggressively to other infections that may or may not have been known before starting HIV meds. Symptoms can include fever, swollen lymph nodes, lesions, rashes, changes in breathing, pneumonia and hepatitis. It's important to report these symptoms to your doctor quickly. In most cases, IRIS can be managed without stopping HIV treatment.

## **HEPATITIS C (HCV)**

There is no vaccine to prevent hepatitis C, and 1 out of 4 people with HIV also have HCV. 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. But it can also be passed through sex, most likely when blood is present in sexual fluids. HIV infection can make hepatitis C worse, and certain HCV strains are harder to treat. It's unclear whether hepatitis C makes HIV worse. Treatment can be difficult to tolerate and is successful in about 2 out of 5 people. However, newer drugs are expected in 2011 which increase the cure rate to 3 out of 4. Seek experienced doctors when making decisions about treating hepatitis C and HIV.

# Managing co-infections and other conditions, *continued*

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## **HEPATITIS B (HBV)**

Nearly 1 out of 4 people with hepatitis B may develop chronic disease; a smaller proportion will develop serious liver problems like cirrhosis. An HBV vaccine will prevent infection in most people. The US Guidelines recommend that co-infected people who need treatment for their HBV should start HIV drugs. Three HIV meds are active against hepatitis B: Viread (also in Truvada, Atripla), Emtriva (also in Truvada, Atripla), and Epivir (also in Combivir, Trizivir). At least one of these should be used as part of the HIV regimen.

## **DIABETES**

Diabetes is common among the general public, and many don't know their risk and go undiagnosed. Women may also develop diabetes during pregnancy. Type 2 diabetes is usually seen as people age, and there's a higher rate of it in HIV-positive people. It's important to be screened before starting an HIV regimen. Some HIV meds, such as protease inhibitors, can contribute to the condition to some degree. It's possible to manage both diabetes and HIV disease, given the various medicines used for both.

## **ORGAN DISEASE**

HIV infection can contribute to diseases of the liver, kidney, heart and other organs. The risk depends upon several factors, such as genetics, your general health, co-infections and lifestyle issues like smoking. HIV meds can also contribute to organ disease, so it's important to know your risks before starting a regimen. For instance, if you have kidney disease, it may be appropriate to avoid Viread, Truvada and Atripla. If you have heart disease, you may want to avoid Ziagen. Other ways that may help include eating healthfully, exercising and stopping smoking.

# Managing co-infections and other conditions, *continued*

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## BONE LOSS

Many HIV-positive people have lower than normal bone mass and are more likely to experience bone loss, perhaps due to HIV itself or ongoing inflammation. However, this doesn't appear to result in a higher risk for fractures or breaks. Certain HIV meds, especially protease inhibitors and NRTIs like Viread, may also contribute to bone loss. Some studies find that this loss levels out within a year or two, but others show continual loss during long-term treatment. Bone density screenings can show existing bone loss. Vitamin D and calcium supplements may help prevent bone problems, and prescription medicines could also be used.



### MAIN POINTS TO REMEMBER:

- It's a good idea to know about any other infections or conditions that you have when treating HIV. This way, you'll have more time to make suitable treatment plans. The conditions on the past three pages are common in HIV-positive people. Other conditions are also possible.

### HELPFUL RESOURCES

- IRIS** [www.projectinform.org/publications/iris/](http://www.projectinform.org/publications/iris/)  
**HCV and Gay Men** [www.projectinform.org/publications/hcv\\_gaymen/](http://www.projectinform.org/publications/hcv_gaymen/)  
**Towards a Healthy Liver** [www.projectinform.org/publications/liver/](http://www.projectinform.org/publications/liver/)  
**Risks to Your Liver** [www.aidsmeds.com/articles/Hepatotoxicity\\_7546.shtml](http://www.aidsmeds.com/articles/Hepatotoxicity_7546.shtml)  
**HIV and Liver Health** [www.poz.com/factsheets/fs\\_2009\\_07\\_liver.pdf](http://www.poz.com/factsheets/fs_2009_07_liver.pdf)  
**Risks to Your Heart** [www.aidsmeds.com/articles/Hyperlipidemia\\_7522.shtml](http://www.aidsmeds.com/articles/Hyperlipidemia_7522.shtml)  
**HIV and Heart Health** [www.poz.com/factsheets/fs\\_2009\\_07\\_heart.pdf](http://www.poz.com/factsheets/fs_2009_07_heart.pdf)  
**Risks to Your Kidneys** [www.aidsmeds.com/articles/kidneys\\_12385.shtml](http://www.aidsmeds.com/articles/kidneys_12385.shtml)  
**Kidney Health and HIV** [www.poz.com/factsheets/fs\\_2009\\_07\\_kidney.pdf](http://www.poz.com/factsheets/fs_2009_07_kidney.pdf)  
**Bone Health and HIV Disease** [www.projectinform.org/publications/bone/](http://www.projectinform.org/publications/bone/)  
**Risks to Your Bones** [www.aidsmeds.com/articles/Bones\\_7548.shtml](http://www.aidsmeds.com/articles/Bones_7548.shtml)

# Herbal products, recreational drugs and HIV medicines

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Using HIV medicines with herbal products, supplements or recreational drugs can sometimes cause serious interactions. It's wise to understand this issue and discuss it with informed professionals. These interactions are not routinely studied, so much of what we know comes from people talking to their doctors or from cases seen in emergency rooms.



A few supplements are known to affect the blood levels of HIV meds. For example, St. John's Wort, garlic supplements and perhaps milk thistle may cause your regimen not to work as well as it could. You may want to speak to your doctor, pharmacist or a trained nutritionist on ways to avoid unwanted interactions.

Using recreational drugs such as ecstasy, ketamine and others along with HIV meds may 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.

## MAIN POINTS TO REMEMBER:

- Some herbal products, including St. John's Wort, garlic supplements and milk thistle, may cause some HIV drugs not work as well as they could.
- Some street drugs, and erection drugs like Viagra, can cause severe and sometimes life-threatening interactions.

## HELPFUL RESOURCES

**Herbs, Recreational Drugs and HIV meds**  
[www.projectinform.org/publications/herbs/](http://www.projectinform.org/publications/herbs/)

**Recreational Drugs and HIV Antiretrovirals**  
[www.projectinform.org/pdf/streetdrugs.pdf](http://www.projectinform.org/pdf/streetdrugs.pdf)

**Consumer Lab** [www.consumerlab.com](http://www.consumerlab.com)

## Consider other aspects of your life

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

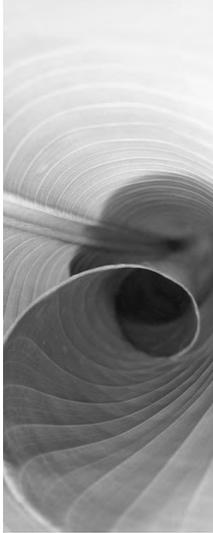


It is also true that life challenges and health issues such as “street drug” abuse, alcohol abuse, domestic violence, mental health issues and homelessness can be very difficult to face on your own. Building a support system of people you trust can be an essential first step. Social services, support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

Support groups for all types of issues (including HIV) can 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 are more plentiful near cities, no matter where you live you can usually find case managers, social workers or peers who can help connect you with local services that can help you with the issues you face.

### MAIN POINTS TO REMEMBER:

- Dealing with HIV may give you the opportunity to change other aspects of your life.
- Many social services are available that can support you making changes.
- Finding and talking to people who understand your situation can be healing and empowering.



## **SELF-ADVOCACY:**

Talking things out

# Getting your health care covered

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In the US, nearly 4 out of 5 people with HIV rely on public programs for their health care. And while you may never need to file for disability, for simplicity we present these options in terms of pre- and post-disability. Disability is a formal claim that must be made with your doctor and approved by Social Security. To find programs you may be eligible for, it's important to consult local resources such as benefits counselors, case managers, social workers or attorneys as programs differ greatly from state to state.

## IF YOU HAVEN'T FILED FOR DISABILITY ...

### GROUP INSURANCE THROUGH YOUR EMPLOYER

If your employer covers health care, 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. Choose a plan that is best for you, and check your plan for HIV-experienced doctors.

### COBRA

If you leave work due to a layoff and had insurance, then you should be offered a continuation policy called COBRA, which is meant to sustain you until you get other insurance. See page 27 for other details.

### INDIVIDUAL PRIVATE INSURANCE

Individual plans are an option, but few people with HIV can purchase them due to high cost and restrictions on pre-existing conditions. If you had coverage before your HIV diagnosis, it's likely most or everything you need will be covered. However, out-of-pocket expenses may be high.

### HIGH RISK INSURANCE POOLS

This program covers people who can't get insurance due to pre-existing conditions and operates in most states. In addition, the federal government is setting up a new program that will operate in all states and DC until 2014 when health care reform is more fully enacted.

### FEDERAL RYAN WHITE PROGRAM

Ryan White funds a broad range of HIV services in states and localities, depending on their unique needs. It's intended to help under- or uninsured people. If you have insurance, you may get help with premiums or other out-of-pocket costs. If you don't have insurance, your state program 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 with your state AIDS program or ASO to see if a Ryan White program can help you.

# Getting your health care covered

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## IF YOU HAVE AN APPROVED DISABILITY CLAIM ...

### COBRA

If you leave work due to disability and had insurance, you'll be offered COBRA until you can get other insurance like Medicare. Coverage is often expensive. Check with a local ASO or state AIDS office for programs to help with out-of-pocket costs.

### MEDICAID

Most people with HIV qualify for 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 below a certain level to qualify. Several states offer Medicaid to all childless adults (AZ, DE, HI, MA, NY and VT), while several others offer some benefits. States vary greatly in what they cover and who qualifies.

### MEDICARE ([www.medicare.gov](http://www.medicare.gov))

If you have held a job, 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 through COBRA, Ryan White or Medicaid.

## OTHER POSSIBLE SOURCES OF HELP

### PATIENT ASSISTANCE PROGRAMS (PAPs)

PAPs are run by HIV drug makers to supply meds to people who are under- or uninsured. They differ widely in eligibility. These are not ideal for the long-term but can help in the short-term or in an emergency.

### VETERANS ADMINISTRATION ([www.hiv.va.gov](http://www.hiv.va.gov))

If you're a veteran or family member, you're eligible for care through the VA. VA sites are only found in some areas and vary in their ability to provide HIV care. As a veteran, you can access Ryan White programs, but if your VA facility is accessible and offers quality HIV care, it may be a good option.

### HELPFUL RESOURCES

- Welvista (access HIV meds for those on ADAP wait lists) [www.welvista.org](http://www.welvista.org)
- Federal resource on health care [www.healthcare.gov](http://www.healthcare.gov)
- High Risk Insurance Pools [www.projectinform.org/publications/highrisk/](http://www.projectinform.org/publications/highrisk/)
- List of PAPs for HIV meds [www.fairpricingcoalition.org](http://www.fairpricingcoalition.org)
- Social Security Administration [www.socialsecurity.gov](http://www.socialsecurity.gov)

## Be flexible with your decision making

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As you begin making decisions about your health and how to treat HIV, understand that decisions may need to change over time. What you decided to do two years ago may not be the best option today. Treatment information changes over time, your health may be different, and your feelings and opinions may have changed.



Giving yourself permission to change your mind can help you be more responsive to new developments in your health and in treatment and care options. For example, you may develop an unexpected infection that causes you to re-evaluate an earlier treatment decision. Or perhaps you start thinking you want to have a baby. Being flexible rather than rigid with your decisions could ease your worries. The new decisions you're making today, though they may feel contrary to earlier ones, can be appropriate at this time.

### MAIN POINTS TO REMEMBER:

- Your treatment decisions may change because of changes in your life, such as pregnancy, a new insurance plan or a new doctor.
- Your feelings change over time, as does treatment information, so your decisions may change over time as well.

# Getting opinions from others

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



However, be careful when using the experiences of others 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 will usually come from well designed clinical studies, since they look at many people taking the same regimen.

HIV treatment guidelines are not meant to be a cookbook, to be applied the same way to everyone. Ask your health providers about their experiences or opinions. Has s/he followed other people using the same medicine(s)? Be open with your doctor about options and the information you read in newsletters and websites.

## MAIN POINTS TO REMEMBER:

- Talking to others about their experiences with treatment can help you think about things you hadn't considered.
- Using more than one source of information can help you make sound treatment decisions.
- Talk to your doctor about his/her experiences with the medicines you're considering.

## Important questions

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### FOR YOUR DOCTOR:

- Do you start every patient on treatment at the same time, or on the same regimen? Why or why not?
- Should I be concerned about HIV meds interacting with other drugs or herbs that I'm taking?
- Should I be concerned about drug resistance, and how do I keep ahead of it?
- What tests or prescriptions are covered by my insurance (public or private)?
- How do blood tests 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 an HIV 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 meds?
- When did you know it was the right time to start?
- What other ways do you keep yourself healthy?
- Do you know of support groups or agencies that help people talk about these decisions?
- How do you make sure you take every dose of your meds every day?
- How did your blood work inform your decision to start?
- Did other things affect your treatment decision?
- What HIV treatment information do you rely on? Why?

## Checklist for getting started

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- I am ready to start taking HIV meds, and understand the reasons why I want to start.
- I am not ready to start taking medicines, and 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 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, or HIV meds and pregnancy.
- I've considered the issues around taking HIV meds and other conditions, like hepatitis C or bone loss.
- I have private or public insurance or another way to 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 is not available, I can call \_\_\_\_\_ or \_\_\_\_\_.

# keeping track of the medicines I take or have taken

Name of medicine or supplement	Start date	Stop date	Side effects I had / reason for stopping / other information
<b>MEDICINES FOR HIV (prezista, truvada, viread, norvir, etc.)</b>			

<b>HIV-RELATED MEDICINES (bactrim, zithromax, diflucan, etc.)</b>			

<b>PRESCRIPTION BIRTH CONTROL (ethinyl estradiol, etc.)</b>			





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[www.projectinform.org/HIVhealth/](http://www.projectinform.org/HIVhealth/)

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