



## HIV SYSTEMS CHECK

### HIV Checklist

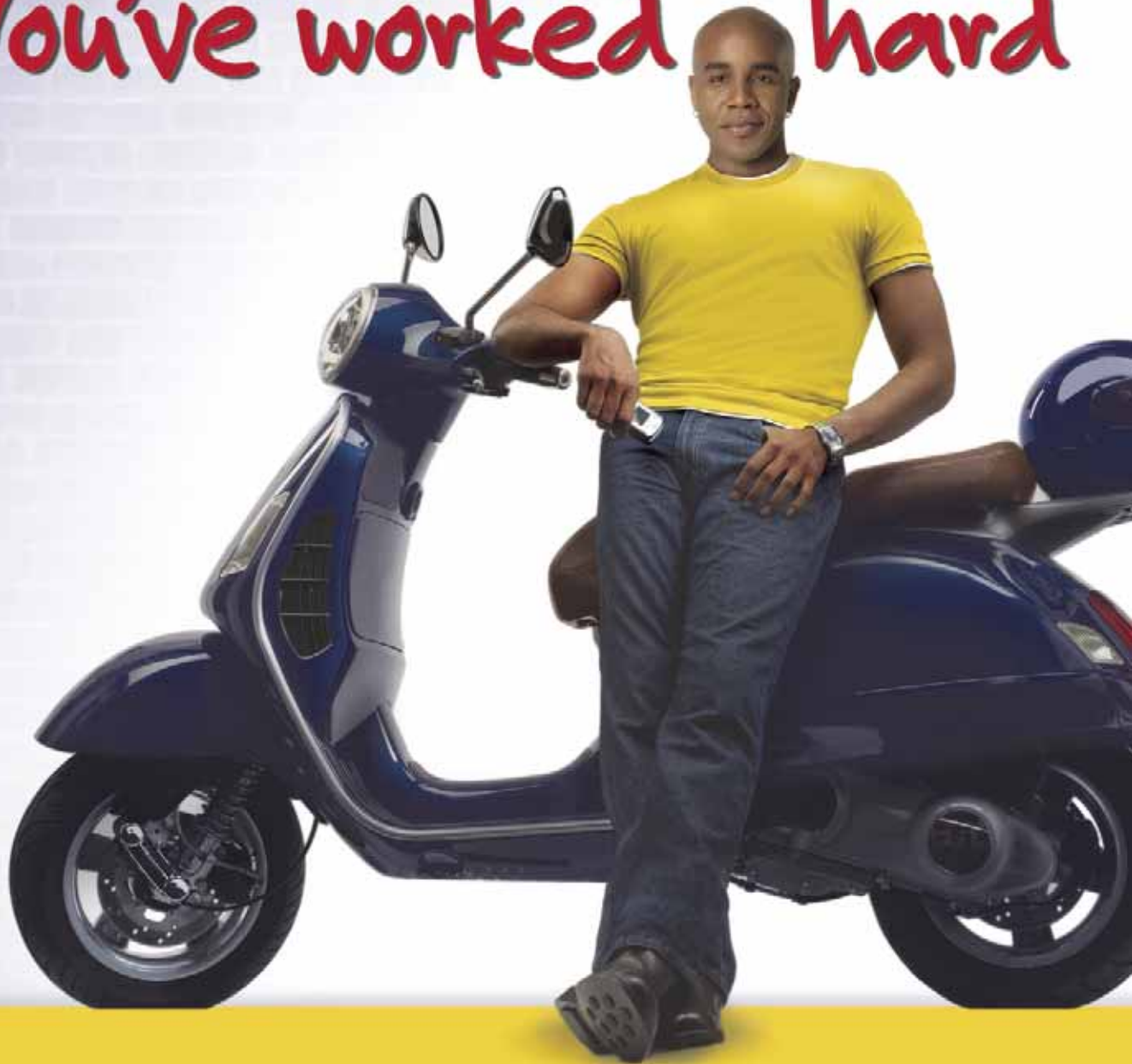
- Nutrition & Lifestyle
- Choosing Your Meds
- Finding a Doctor
- Mental Health
- Understanding Labs



VIRAL LOAD • CD4s • LIVER • KIDNEYS • LIPIDS

In combination with other antiretroviral agents for the treatment of HIV-1 infection in adults

# You've worked hard



TRUVADA<sup>®</sup> does not cure HIV infection or lower your chance of passing HIV-1 to others and must be used as part of combination therapy. **TRUVADA should not be used with VIREAD<sup>®</sup>, EMTRIVA<sup>®</sup>, Combivir<sup>®</sup>, Epivir<sup>®</sup>, Epivir-HBV<sup>®</sup>, Epzicom<sup>™</sup>, or Trizivir<sup>®</sup>.**

#### USE OF TRUVADA:

TRUVADA is indicated in combination with other antiretroviral agents (such as nonnucleoside reverse transcriptase inhibitors or protease inhibitors) for the treatment of HIV-1 infection in adults.



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#### IMPORTANT SAFETY INFORMATION:

- **Lactic acidosis** (a buildup of acid in the blood) can be a medical emergency and may need to be treated in the hospital. Call your healthcare provider right away if you have nausea, vomiting, unusual muscle pain, and/or weakness
- **Serious liver problems** (hepatotoxicity), with liver enlargement (hepatomegaly) and fat in the liver (steatosis), may occur. **Call your healthcare provider right away** if you have light colored stools, dark colored urine, and/or if your skin or the whites of your eyes turn yellow
- **Flare-ups of hepatitis B virus (HBV) infection:** If you have HIV and HBV, your liver disease may suddenly get

# to get where you are.

## So why settle for an HIV med that's twice a day?

Once-a-day TRUVADA® can help get you to undetectable and keep you there. As part of an HIV regimen, the meds in TRUVADA:

- Can be taken with or without food
- Reduce viral load and increase CD4 cell count

Ask your doctor how TRUVADA can be part of a complete once-a-day regimen.



**Truvada**®

200 mg emtricitabine - tenofovir disoproxil fumarate 300 mg

*Move On With Life*

**TRUVADA is the #1 Prescribed HIV Med\***

worse if you stop taking TRUVADA. Do not stop taking TRUVADA unless directed by your healthcare provider

- **Kidney problems:** If you have had kidney problems or take other medicines that can cause kidney problems, your healthcare provider should do regular blood tests to check your kidneys
- **Bone changes:** It is not known whether long-term use of TRUVADA causes damage to your bones. If you have had bone problems in the past, talk to your healthcare provider before taking TRUVADA

Changes in body fat have been seen in some people taking anti-HIV medicines. The most common side effects of TRUVADA when taken with other anti-HIV medicines are

dizziness, diarrhea, nausea, vomiting, headache, abdominal pain, depression, rash, and gas. Skin discoloration (spots and freckles) may also occur.

**Discuss all medicines you take with your healthcare provider and be aware:**

- Your healthcare provider may need to follow you more closely or adjust your therapy if you are taking Videx®, Videx® EC, Reyataz®, or Kaletra® with TRUVADA

For more information, please visit [www.truvada.com](http://www.truvada.com) or call **1-800-GILEAD-5 (1-800-445-3235)** and select option 2. **There is additional information about TRUVADA on the next page.**

\*Based on data from PHAST retail monthly data; April 2006–June 2006; Wolters Kluwer Health.

## Patient Information

### TRUVADA® (tru-VAH-dah) Tablets

Generic name: emtricitabine and tenofovir disoproxil fumarate  
(em tri SĪT uh bean and te NOĒ fo veer dye soe PROX il FYOU-mar-ate)

Read the Patient Information that comes with TRUVADA before you start taking it and each time you get a refill. There may be new information. This information does not take the place of talking to your healthcare provider about your medical condition or treatment. You should stay under a healthcare provider's care when taking TRUVADA. **Do not change or stop your medicine without first talking with your healthcare provider.** Talk to your healthcare provider or pharmacist if you have any questions about TRUVADA.

### What is the most important information I should know about TRUVADA?

• **Some people who have taken medicine like TRUVADA (nucleoside analogs) have developed a serious condition called lactic acidosis** (buildup of an acid in the blood). Lactic acidosis can be a medical emergency and may need to be treated in the hospital. **Call your healthcare provider right away if you get the following signs or symptoms of lactic acidosis.**

- You feel very weak or tired.
- You have unusual (not normal) muscle pain.
- You have trouble breathing.
- You have stomach pain with nausea and vomiting.
- You feel cold, especially in your arms and legs.
- You feel dizzy or lightheaded.
- You have a fast or irregular heartbeat.

• **Some people who have taken medicines like TRUVADA have developed serious liver problems called hepatotoxicity**, with liver enlargement (hepatomegaly) and fat in the liver (steatosis). **Call your healthcare provider right away if you get the following signs or symptoms of liver problems.**

- Your skin or the white part of your eyes turns yellow (jaundice).
- Your urine turns dark.
- Your bowel movements (stools) turn light in color.
- You don't feel like eating food for several days or longer.
- You feel sick to your stomach (nausea).
- You have lower stomach area (abdominal) pain.

• **You may be more likely to get lactic acidosis or liver problems** if you are female, very overweight (obese), or have been taking nucleoside analog medicines, like TRUVADA, for a long time.

• **TRUVADA is not for the treatment of Hepatitis B Virus infection.** Patients infected with both HBV and human immunodeficiency virus (HIV) who take TRUVADA need close medical follow-up for several months after stopping treatment with TRUVADA. Follow-up includes medical exams and blood tests to check for HBV that could be getting worse. **Patients with Hepatitis B Virus infection, who take TRUVADA and then stop it, may get "flare-ups" of their hepatitis. A "flare-up" is when the disease suddenly returns in a worse way than before.**

### What is TRUVADA?

TRUVADA is a type of medicine called an HIV (human immunodeficiency virus) nucleoside analog reverse transcriptase inhibitor (NRTI). TRUVADA contains 2 medicines, EMTRIVA® (emtricitabine) and VIREAD® (tenofovir disoproxil fumarate, or tenofovir DF) combined in one pill. TRUVADA is always used with other anti-HIV medicines to treat people with HIV infection. TRUVADA is for adults age 18 and older. TRUVADA has not been studied in children under age 18 or adults over age 65.

HIV infection destroys CD4 (T) cells, which are important to the immune system. The immune system helps fight infection. After a large number of T cells are destroyed, acquired immune deficiency syndrome (AIDS) develops.

TRUVADA helps block HIV reverse transcriptase, a chemical in your body (enzyme) that is needed for HIV to multiply. TRUVADA lowers the amount of HIV in the blood (viral load). TRUVADA may also help to increase the number of T cells (CD4 cells). Lowering the amount of HIV in the blood lowers the chance of death or infections that happen when your immune system is weak (opportunistic infections).

**TRUVADA does not cure HIV infection or AIDS.** The long-term effects of TRUVADA are not known at this time. People taking TRUVADA may still get opportunistic infections or other conditions that happen with HIV infection. Opportunistic infections are infections that develop because the immune system is weak. Some of these conditions are pneumonia, herpes virus infections, and *Mycobacterium avium* complex (MAC) infection. **It is very important that you see your healthcare provider regularly while taking TRUVADA.**

**TRUVADA does not lower your chance of passing HIV to other people through sexual contact, sharing needles, or being exposed to your blood.** For your health and the health of others, it is important to always practice safer sex by using a latex or polyurethane condom or other barrier to lower the chance of sexual contact with semen, vaginal secretions, or blood. Never use or share dirty needles.

### Who should not take TRUVADA?

Do not take TRUVADA if you are allergic to TRUVADA or any of its ingredients. The active ingredients of TRUVADA are emtricitabine and tenofovir DF. See the end of this leaflet for a complete list of ingredients.

### What should I tell my healthcare provider before taking TRUVADA?

Tell your healthcare provider if you:

- **are pregnant or planning to become pregnant.** We do not know if TRUVADA can harm your unborn child. You and your healthcare provider will need to decide if TRUVADA is right for you. If you use TRUVADA while you are pregnant, talk to your healthcare provider about how you can be on the TRUVADA Antiviral Pregnancy Registry.
- **are breast-feeding.** You should not breast-feed if you are HIV-positive because of the chance of passing the HIV virus to your baby. Also, it is not known if TRUVADA can pass into your breast milk and if it can harm your baby. If you are a woman who has or will have a baby, talk with your healthcare provider about the best way to feed your baby.
- **have kidney problems or are undergoing kidney dialysis treatment.**
- **have bone problems.**
- **have liver problems including Hepatitis B Virus infection.**

**Tell your healthcare provider about all the medicines you take**, including prescription and non-prescription medicines, vitamins, and herbal supplements. Especially tell your healthcare provider if you take:

- COMBIVIR®, EMTRIVA, EPIVIR®, EPIVIR-HBV®, EPZICOM™, TRIZIVIR®, or VIREAD. **TRUVADA should not be used with those medicines.**
- Drugs that contain didanosine (VIDEX®, VIDEX EC®). Tenofovir DF (a component of TRUVADA) may increase the amount of VIDEX in your blood. **You may need to be followed more carefully if you are taking TRUVADA and VIDEX together.**
- REYATAZ® (atazanavir sulfate) or KALETRA® (lopinavir/ritonavir). These medicines may increase the amount of tenofovir DF (a component of TRUVADA) in your blood, which could result in more side effects. You may need to be followed more carefully if you are taking TRUVADA and REYATAZ or KALETRA together.

Keep a complete list of all the medicines that you take. Make a new list when medicines are added or stopped. Give copies of this list to all of your healthcare providers and pharmacist **every** time you visit your healthcare provider or fill a prescription.

### How should I take TRUVADA?

- Take TRUVADA exactly as your healthcare provider prescribed it. Follow the directions from your healthcare provider, exactly as written on the label.
- The usual dose of TRUVADA is 1 tablet once a day. TRUVADA is always used with other anti-HIV medicines. If you have kidney problems, you may need to take TRUVADA less often.
- TRUVADA may be taken with or without a meal. Food does not affect how TRUVADA works. Take TRUVADA at the same time each day.
- If you forget to take TRUVADA, take it as soon as you remember that day. **Do not take more than 1 dose of TRUVADA in a day. Do not take 2 doses at the same time.** Call your healthcare provider or pharmacist if you are not sure what to do. **It is important that you do not miss any doses of TRUVADA or your anti-HIV medicines.**
- When your TRUVADA supply starts to run low, get more from your healthcare provider or pharmacy. This is very important because the amount of virus in your blood may increase if the medicine is stopped for even a short time. The virus may develop resistance to TRUVADA and become harder to treat.
- Do not change your dose or stop taking TRUVADA without first talking with your healthcare provider. Stay under a healthcare provider's care when taking TRUVADA.
- If you take too much TRUVADA, call your local poison control center or emergency room right away.

### What should I avoid while taking TRUVADA?

- **Do not breast-feed.** See "What should I tell my healthcare provider before taking TRUVADA?"
- **Avoid doing things that can spread HIV infection** since TRUVADA doesn't stop you from passing the HIV infection to others.
  - **Do not share needles or other injection equipment.**
  - **Do not share personal items that can have blood or body fluids on them, like toothbrushes or razor blades.**
  - **Do not have any kind of sex without protection.** Always practice safer sex by using a latex or polyurethane condom or other barrier to reduce the chance of sexual contact with semen, vaginal secretions, or blood.
- COMBIVIR, EMTRIVA, EPIVIR, EPIVIR-HBV, EPZICOM, TRIZIVIR, or VIREAD. **TRUVADA should not be used with these medicines.**

### What are the possible side effects of TRUVADA?

**TRUVADA may cause the following serious side effects** (see "What is the most important information I should know about TRUVADA?"):

- **Lactic acidosis** (buildup of an acid in the blood). Lactic acidosis can be a medical emergency and may need to be treated in the hospital. **Call your doctor right away if you get signs of lactic acidosis.** (See "What is the most important information I should know about TRUVADA?")
- **Serious liver problems (hepatotoxicity)**, with liver enlargement (hepatomegaly) and fat in the liver (steatosis). Call your healthcare provider right away if you get any signs of liver problems. (See "What is the most important information I should know about TRUVADA?")
- **"Flare-ups" of Hepatitis B Virus infection**, in which the disease suddenly returns in a worse way than before, can occur if you stop taking TRUVADA. Your healthcare provider will monitor your condition for several months after stopping TRUVADA if you have both HIV and HBV infection. TRUVADA is not for the treatment of Hepatitis B Virus infection.

- **Kidney problems.** If you have had kidney problems in the past or take other medicines that can cause kidney problems, your healthcare provider should do regular blood tests to check your kidneys.

- **Changes in bone mineral density (thinning bones).** It is not known whether long-term use of TRUVADA will cause damage to your bones. If you have had bone problems in the past, your healthcare provider may need to do tests to check your bone mineral density or may prescribe medicines to help your bone mineral density.

Other side effects with TRUVADA when used with other anti-HIV medicines include:

- Changes in body fat have been seen in some patients taking TRUVADA and other anti-HIV medicines. These changes may include increased amount of fat in the upper back and neck ("buffalo hump"), breast, and around the main part of your body (trunk). Loss of fat from the legs, arms, and face may also happen. The cause and long-term health effects of these conditions are not known at this time.

The most common side effects of EMTRIVA or VIREAD when used with other anti-HIV medicines are: dizziness, diarrhea, nausea, vomiting, headache, abdominal pain, depression, rash, and gas. Skin discoloration (small spots or freckles) may also happen with TRUVADA.

These are not all the side effects of TRUVADA. This list of side effects with TRUVADA is **not complete** at this time because TRUVADA is still being studied. If you have questions about side effects, ask your healthcare provider. Report any new or continuing symptoms to your healthcare provider right away. Your healthcare provider may be able to help you manage these side effects.

### How do I store TRUVADA?

- **Keep TRUVADA and all other medicines out of reach of children.**
- Store at room temperature up to 77 °F (25 °C).
- Keep TRUVADA in its original container and keep the container tightly closed.
- Do not keep medicine that is out of date or that you no longer need. If you throw any medicines away make sure that children will not find them.

### General information about TRUVADA:

Medicines are sometimes prescribed for conditions that are not mentioned in patient information leaflets. Do not use TRUVADA for a condition for which it was not prescribed. Do not give TRUVADA to other people, even if they have the same symptoms you have. It may harm them.

This leaflet summarizes the most important information about TRUVADA. If you would like more information, talk with your healthcare provider. You can ask your healthcare provider or pharmacist for information about TRUVADA that is written for health professionals. For more information, you may also call 1-800-GILEAD-5 or access the TRUVADA website at [www.TRUVADA.com](http://www.TRUVADA.com).

Do not use TRUVADA if seal over bottle opening is broken or missing.

### What are the ingredients of TRUVADA?

**Active Ingredients:** emtricitabine and tenofovir DF

**Inactive Ingredients:** Croscarmellose sodium, lactose monohydrate, magnesium stearate, microcrystalline cellulose, and pregelatinized starch (gluten free). The tablets are coated with Opady II Blue Y-30-10701 containing FD&C Blue #2 aluminum lake, hypromellose, lactose monohydrate, titanium dioxide, and triacetin.

### Rx Only

January 2005

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# Fall 2006 • Special Issue



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You can view these (and other stories from previous issues) online at [www.tpan.com](http://www.tpan.com)

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This special *Positively Aware* (PA) supplement is made possible through the exclusive support of  
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## EDITOR'S NOTE

### The Deluxe Tune-up Issue



It's quite an honor to be asked to be the guest editor for a treatment magazine I value, from an organization whose work I respect, by people whom I admire. What more could one activist want? Oh, and I got to pick the writers!

Really good, useful HIV/AIDS treatment information is actually harder to write than it looks. You'll be the judge of how well we did in this issue, of course, but I already feel good about one thing: it was put together by people who are immersed in the fight against HIV/AIDS—some of us live in it and some of us work in it and some of us do both—and it's written for the very same kinds of people.

When I was asked to be the editor of this issue and was given a rough outline of the "systems check" idea, I immediately started thinking about how to approach each topic and with whom to do it. I wanted people who one, were committed to HIV education and passionate about helping people live well with HIV/AIDS and two, would speak their truths—not what they've read in some guidelines or heard at a lecture, but what they know to be true from their lives and work. That much, I know I got right.

Greg Milward moved to Madison, Wisconsin, from Washington, D.C. I asked him to write about choosing a doctor because he had told me about his move here and how he feared that he'd have to commute to D.C. for his health care. How could he find physicians in this small city who he would feel as confident about as he did at Johns Hopkins and Georgetown? I thought he'd write about that but, instead, he wrote about his first experience with an HIV provider. I realized—and his story is really about this—that his search for good care in a small midwestern city was nothing he couldn't handle because his first experience forced him to learn everything he needed.

Once you find a good provider, how do you maintain a productive, healthy relationship with that person? By way of discussing this, Greg and I decided to share with you a conversation we had about our experiences as patients in the doctor-patient relationship. It crossed our minds that there should be something like marriage counselors for people and their physicians. You'll see what we mean.

There are some nuts-and-bolts parts of this issue, like which lab tests are key to good care and what goes into treatment decisions. I went to two other Midwesterners for these.

Melissa Ngo is a pharmacist I met when she started working in our Friday prisoner clinic. She was new to HIV, but I was struck by how eager she was to learn and how involved she became in the treatment of HIV disease. Melissa's piece on making antiretrovirals work for you is from the perspective of someone who's counseled

people on HIV medications in clinic, in the outpatient pharmacy, and on the phone through the mail-order program. She sees it from every side and she was willing to share what she's learned with us.

Judith Feinberg is a clinician and researcher in Cincinnati, Ohio. She has years of HIV/AIDS experience that she agreed to lend to this issue by way of a piece on lab tests. This is a subject people often leave to their provider and don't know much about, but Judith lets us know exactly why these tests are important and how they help us figure out how things are working in the places we can't always see or feel.

I foiled my plot to have "all Midwesterners, all the time" for this issue when I realized there were some people I knew who could speak expertly and thoughtfully to some key issues...and they didn't live in these parts. Although I'm eager to do what I can to help readers (and my activist colleagues!) from the coasts appreciate the smarts and skills that reside in the Midwest, I made a good decision.

Charlie Smigelski is a registered dietician from Boston who knows his way around nutrition, supplementation and other strategies to maximize the possibility for living well and long with HIV/AIDS. His piece is about those nagging problems—high lipids, gut distress, fatigue—that resonate for a lot of people. Sure, we're living longer, but that means we're on a bunch of meds for a long time, we have to think about diseases of older age and—you know this is true—we're not in the shape we used to be. Fortunately, Charlie has some helpful information for us all.

I met Tonia Poteat, a physician's assistant from Atlanta, at a meeting about women and HIV/AIDS. It was clear to me that the HIV-positive women she treats at the Grady Infectious Disease Program and her years of HIV/AIDS advocacy before becoming a provider informed her perspective in a wonderful way. She graciously agreed to write about three critical influences on our mental health—depression, anxiety, and addiction.

So, there you have it. I hope this "systems check" issue is helpful. It's important to take a look with fresh eyes at those things you're so used to that you don't even really see anymore. Remember the words (more or less) of the great philosopher, Ice Cube: Check yourself before you wreck yourself.

Heidi M. Nass



# Lessons I Learned from Dr. Cruise Control

How one man's search for a doctor taught him to be an active participant in his own health care

by Greg Milward

It's impossible to write about choosing a health care provider without reflecting on my first experience as an HIV patient. It was many years ago, fresh from the hospital after a three-week stay with *Pneumocystis pneumonia* (PCP), when I found myself in the feng shui-inspired office of an infectious disease specialist in Washington, D.C. The calm, soothing environment provided no help for what came next.

Three minutes into the appointment he handed me a stack of prescriptions for HIV medications and told me to go to the pharmacy and get them filled. I asked a few questions about what was being prescribed when he abruptly told me to "just take the pills and you'll be on cruise control."

"What are you talking about?" I asked. His response was a simple, "Like I said, just take your pills and you'll be on cruise control for the rest of your life." Once again, I started to ask some questions about his prescribed course of treatment. His irritation with me became obvious and he got up to leave the exam room.

Newly diagnosed, out of the hospital for just three days, and my first appointment with my new doctor lasted less than

five minutes. Actions really do speak louder than words and it was apparent from his actions that Dr. Cruise Control was dismissing my concerns and questions as irrelevant. After all, it seemed, I was just the patient; he was the doctor.

After telling me to make a follow-up appointment in three months (three months!), he left me sitting there in the exam room. I was dumbfounded. I sat there and started to cry.

Needless to say, that was the last time I saw that doctor. Cruise control is meant for automobiles—not for someone recently diagnosed with HIV or who's still getting used to the words "you have AIDS."

I look back at that experience and realize that even though my relationship with Dr. Cruise Control was short-lived, he provided a valuable lesson. In that brief encounter, it became clear that I needed to become a wise consumer of health care services; I needed to set in place a process that would help me to make a well thought-out decision as to who I would trust to be an integral part of my health care team.

After my encounter with Dr. Cruise Control I set out to find a doctor that would

work with me as a partner in my care. The most important factor in my search was coming to the realization that any doctor that I would work with from this point forward also had to be a healer.

What do I mean by "healer"? It's simple: I will not entrust my care to someone who does not care for me in a holistic manner—he or she has to treat me as a whole person, not simply as a virus who happens to be living within a human being.

A healer is as concerned about how I am feeling as he or she is with the numbers on my quarterly blood work. A healer works with me as an equal partner in my care. A healer talks *with* me rather than talking *at* me. Healers encourage me to be an active part of my care and are not threatened by the fact that I may want to explore complementary therapies as a part of my health care. They are willing to admit that they do not have all of the answers and don't expect me to put them on a pedestal and accept every word as gospel.

I realized that I needed to be able to ask questions and bring thoughts, suggestions, and questions to my appointments. I needed to be able to have any concerns or questions

## TIP SHEET FOR FINDING A GOOD HIV CARE PROVIDER

1. Learn as much as you can and are willing to about HIV/AIDS because this will put you in a better position to make good assessments. Focus on finding a physician with whom you can be totally honest...and it feels okay to do so.
2. Get clear about how your health care will be paid for—do you have something that pays for your health care—insurance? Medicare? Medicaid? Do you need a doctor who can provide care even if you don't have a way to pay?
3. Ask some key questions of the physician.
  - Why do you practice in HIV/AIDS?
  - How many people with HIV/AIDS do you currently have in your practice?
  - How long have you been practicing medicine in HIV/AIDS?

- What's your idea of a good doctor-patient relationship—doctor in charge? Patient in charge? Team approach?
- Are you reachable by phone if I have an emergency? Who covers for you when you're not available?
- Are you an HIV specialist? What are your credentials?

If you can, get yourself to a computer and check out the following resources:

### AMERICAN ACADEMY OF HIV MEDICINE

On this site you can find a physician in your area who is an HIV specialist according to the American Academy of HIV Medicine (AAHIVM). The AAHIVM has established a definition for "credentialed HIV Specialist" using industry-standard criteria to measure

knowledge—experience, education, and external validation. To receive and maintain credentials, a provider (physician, osteopath, physician assistant, or nurse practitioner) must continuously fulfill the requirements of the AAHIVM. Requirements include being licensed, passing a credentialing exam, taking regular courses, and maintaining a patient caseload of at least 20 every two years. Visit [www.aahivm.org](http://www.aahivm.org).

### THEBODY.COM

The Body has organized a variety of information from various sources on the topic of "Choosing and Working with a Provider." The collection includes basic information, personal accounts, research, and resources. Visit [www.thebody.com/choosing/html](http://www.thebody.com/choosing/html).

addressed without being made to feel like a fool. I also decided after my experience with Dr. Cruise Control that any doctor I worked with had to have specialized knowledge and experience in the treatment of HIV/AIDS. While there are many talented doctors, I wanted a provider who was at the forefront of treating HIV. I decided that I wouldn't consider any provider who did not have a significant HIV practice.

Once I tentatively decided who was going to replace Dr. Cruise Control, I had a conversation with the prospective new doctor about what his expectations were of me as a patient. Interestingly, his expectations of me were very similar to the expectations I had of him.

He asked that I be open-minded to suggestions and come to my appointments willing to discuss various treatment options. He asked for my continuing honesty about issues going on in my life and with my health, and he asked that I make a commitment to continue my education on issues related to living with HIV.

The thing that really made me realize that it was going to be a good match was when he told me that he approached his relationship with patients as a partnership—with both patient and doctor having


*I needed to be able to have any concerns or questions addressed without being made to feel like a fool.*

a shared responsibility. He shared his belief that patients, when given the opportunity to work with their doctors as equal partners in their care can, in many ways, become their own doctors.

At that moment I remembered a quote I had read the day before that was written many years ago by Albert Schweitzer. He said, "Each patient carries his own doctor inside him. They come to us not knowing that truth. We are at our best when we give

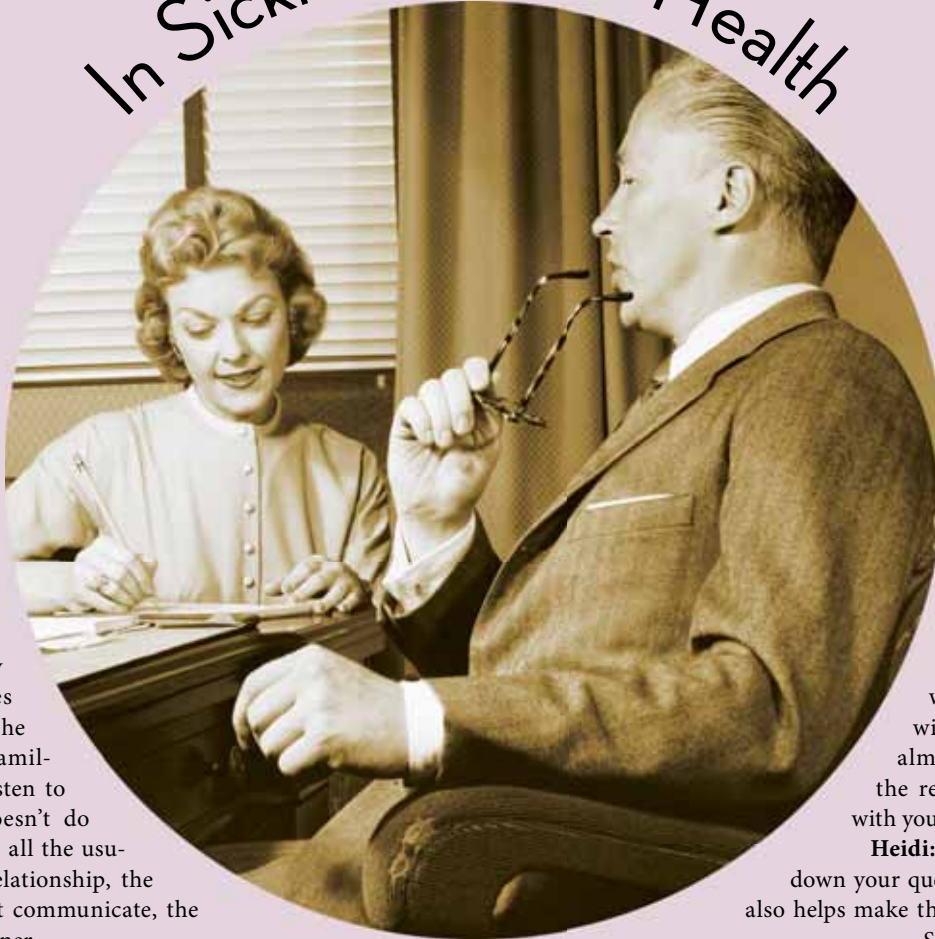
the doctor who resides within each patient a chance to go to work." It was clear that my new doctor was empowering me—the patient—to be an active participant in my care and to awaken the "doctor" that resides within me.

The final question I asked him was whether he saw any parallels between living with HIV and being on cruise control. He laughed. He said he wished it was that simple, but it was clear that cruise control was meant for automobiles and had no place in a philosophy of HIV care.

I knew I had made the right decision. 

*Greg Milward recently returned to his birthplace of Madison, Wisconsin, after 20 years in Tucson, Santa Fe and Washington, D.C. He shares his life with his partner of 24 years and the two best Labrador Retrievers in the world. He is happy to report that his approach to finding a good health care provider led him to the University of Wisconsin HIV Care Program and Dr. Frank Graziano, with whom he shares "a wonderful doctor/patient relationship." He can be reached at [gregmilward@charter.net](mailto:gregmilward@charter.net).*

# In Sickness and in Health



If you listen to enough people talk about what happened at their latest doctor's appointment, you start to get the sense that there's a bunch of patients and physicians out there who could really use some couples counseling. Even the language sounds familiar: "He doesn't listen to me," and "She doesn't do what I say." There's all the usuals—the healthy relationship, the couple who doesn't communicate, the unappreciated partner, the bully.

The doctor-patient relationship is an important one if we want to stay healthy and especially when we're sick. The beauty of this relationship is that we don't need to stay together for the kids, so we might as well find one that works.

Recently, I had the pleasure of sitting down with Greg Milward to talk about our failed relationships and those that have worked, and what it is that makes the difference. What follows is part of our conversation.

**Heidi:** Greg, how do you go about asking questions and raising concerns with your medical provider?

**Greg:** Going into my appointment with my doctor, I recognize that I have a limited amount of time to spend with him and I do some things to maximize the time. First, I prepare a memo to the doctor that does three things. It updates him on issues or problems we discussed at our last appointment. Second, I list issues that I need to discuss with him at this appointment. These can be medication issues such as side effects or other problems that I am having. Finally, I list any other general questions I have for him. I find that having put things in writing helps to make sure that all of the issues I want to cover are dealt with. My doctor also likes this because he then has something that he can put in my file that lists the issues

that I brought to him to discuss.

In busy clinics, the best ally you can usually have is the other staff in the clinic. Get to know the nurses, physician's assistants and front desk personnel. Having a good working relationship with the clinic staff is almost as important as the relationship you have with your doctor.

**Heidi:** I think that writing down your questions and concerns also helps make them real, so to speak.

Sometimes, as a means of coping, we minimize or deny what we're going through. Consequently, it's harder to bring those things up

when we're sitting in an exam room in front of our doctors, who may or may not be distracted, or focused on some other aspect of our health, or tired from whatever else they've got going on in their lives. If we write those things down, my guess is that we are much less likely to ignore them ourselves, and much more likely to treat them like the real things they are.

Do you feel like HIV-related issues form the boundary of what you bring to your HIV provider or do you approach your doctor with broader issues than that?

**Greg:** In my case, nothing is off limits in what I will ask my doctor about, primarily due to the fact that my infectious disease doctor also functions as my primary care provider. This isn't always the case. In situations where you are seeing an infectious disease specialist for issues related to HIV, some think that it should limit what issues you would bring to your appointment to discuss. I don't agree with this. Let the doctor decide whether or not issues are related and, if necessary, provide a referral to a specialist to deal with other issues.

**Heidi:** That's an important point. Some physicians trained in a particular medical specialty may not be that eager to do what

## A conversation about doctor-patient relationships by Heidi M. Nass with Greg Milward

amounts to primary care, even though many would argue that good long-term HIV care necessarily requires it. Someone who is an infectious disease specialist, for example, might be more focused on infections that get cleared and may not be all that interested in monitoring heart disease risk, managing diabetes, etc.—the stuff that’s necessary in a lifelong infection like HIV. It’s my opinion that the physician who feels that way should consider getting out of HIV practice.

Like it or not, HIV is a complicated, long-term infection that requires specialized care. Some HIV patients don’t have health coverage, so having another doctor to deal with their non-HIV issues is out of the question. Besides, it can be a challenge to distinguish what’s HIV-related from what’s not.

As a patient, it doesn’t take long to figure out that non-HIV providers often don’t really have a clue about how HIV and antiretroviral therapy intersects with other “regular” health issues...which doesn’t lend itself to good, comprehensive care.

There must be some questions or issues you find harder to bring up than others. I mean, the doctor’s office can be an intimidating place and there’s this thing that a lot of people have about, well, wanting your doctor to like you, you know? Plus, this is the person who writes the prescription for that medication you need and decides whether to order that lab test you want—let’s face it, you don’t get that far without this person’s okay. Even beyond that, I’m not sure all patients get the signal from the doctor that “anything goes.” So, what are the kinds of things you’ve maybe had to work at to put on the table with your doctor?

**Greg:** The hardest issues for me to discuss with my doctor have been related to pain associated with peripheral neuropathy and fatigue. Chronic pain is hard to describe and, for me, there was an irrational fear when I first started to experience it that my doctor would think it was all in my head. Fatigue was also a hard one to discuss, at first. I quickly got over that, though, when my doctor convinced me that confronting issues related to fatigue was one of the key factors in improving a person’s quality of life.

I know this sounds strange, but I also think that in the early days after the advent of HAART (highly active anti-retroviral therapy) there was a sense of survivor’s guilt that made issues like pain and fatigue hard to discuss. After all, we had watched friends die of this disease and, for me, early on in my relationship with HIV medications there was a sense that I needed to be grateful to have the medications and just needed to deal with what I thought at the time were the “minor” issues related to fatigue and neuropathy.

**Heidi:** I have to think there’s been a time that you didn’t agree with your doctor’s approach to an issue. How do you handle that kind of thing?

**Greg:** With my first doctor, I disagreed with his approach to the relationship between doctor and patient. I was expected to simply be the subservient patient. Since that failed doctor-patient relationship, I’ve been fortunate and can honestly say that I’ve never disagreed with my doctor’s approach. I think that’s because with both doctors I’ve had the privilege of working with since my first doctor, the relationship has been one where I was able to openly discuss, question, debate and ultimately decide with my doctor what course of treatment was going to be taken.

What about you?

**Heidi:** I guess my ride has been a bit bumpier but it got me to my current doctor, so it was worth it, I suppose. I’ve had providers who’ve kind of drawn some weird lines in the sand that felt a little

power trippy to me and, to be honest, I found it hard to recover from that and stay in the relationship. What I really appreciate about my current doctor—and this seems like a bit of a lost art in medicine—is that he listens without the interference of his ego. I didn’t say he has no ego, mind you, and I joke that I don’t want to be the last appointment on his marathon clinic schedule, but I’ll take his willingness to take *me* into account any day. I like to say that what makes it work is that he knows his place and I know mine—he’s the advisor and expert and advocate, and I’m the one who lives with this virus.

What do you do if you aren’t getting what you need from your provider?

**Greg:** First, remember that you are the “consumer.” If you don’t feel that you are getting what you need from your provider I would approach it head on. Is it just not a “good fit”? This can be nothing more than a gut feeling that you don’t click with a particular provider—you don’t like his or her bedside manner. A doctor may be a brilliant clinician, but if you don’t feel that you can bring issues to him or her to talk about open and freely, then it’s probably not a relationship that will work in the long run.

**Heidi:** Amen. I am continually surprised by the blind trust that some people have in their providers. I’ve heard people say, “Well, I wouldn’t want my doctor to think I’m challenging him in any way. He’s the expert, not me.” That scares me a little. There are brilliant physicians, of course, and there are also overworked physicians, physicians who don’t keep current with research, physicians who don’t treat much HIV, and, frankly, physicians who just aren’t very good. My feeling is that—and I had to summon my courage early on to say this once to a physician who was skilled but was just not listening to me—when I leave the exam room, HIV comes with me; unlike you, I live with this disease, and I will die with it. That means that there are some things I am the expert on, like how I want to live with this and what I want my care to be like.

**Greg:** I’m guessing you no longer get care from that physician, yes?

**Heidi:** You got it.

If you could only say a few words to someone newly diagnosed about getting the most out of the patient-provider relationship, what would you say? This is your chance to create a motto, Greg!

**Greg:** Trust your gut instinct—does the relationship with your doctor feel right? Don’t be afraid to change doctors if you don’t feel you are getting the care you deserve. Also, remember that getting the most out of your relationship is a shared responsibility between you and the provider.

What about you? What’s the message you’d give to someone just setting out?

**Heidi:** Hmmm. The big thing I think about is that your doctor gets to leave HIV when the workday is done; you don’t. If you’re not all that interested or involved in your care, why should anyone else be? Even if your doctor sometimes wishes you were less involved, shall we say, at least it becomes clear that you are in it for real—you’re here to take care of yourself. I’m pretty confident that leads to better care. ☞

*Heidi M. Nass is a lawyer turned treatment advocate and educator. She is based in Madison, Wisconsin, at the University of Wisconsin HIV Care Program. She may be reached at [hmn@medicine.wisc.edu](mailto:hmn@medicine.wisc.edu).*

# The 10-Point Inspection, HIV-Style: What to Check Under the Hood

## SOME OF THE MOST IMPORTANT TESTS, AND WHAT THEY MEAN

BY JUDITH FEINBERG, MD

In many parts of the world, medical providers care for their patients who have HIV/AIDS without the benefit of laboratory tests—sometimes even the most basic ones. Fortunately, in the United States (and various other countries), medical providers almost always have available to them a wide range of diagnostic tools. Below are ten (plus three) of the most important ones.

**1. Complete blood count (CBC).** This tells you whether you are anemic (too few red blood cells), neutropenic (too few of the white blood cells called neutrophils that fight bacterial infections) or thrombocytopenic (too few platelets, or thrombocytes, for your blood to clot normally)—all of which occur commonly in people with HIV. The CBC also gives you something called the “differential,” which is an individual count of all the different kinds of white blood cells: neutrophils, monocytes, lymphocytes, basophils, and eosinophils. It is also crucial to determining your total CD4 (T4, T helper) cell count, a critical measure of immune function.

**2. CD4 cell count.** The FACS (not “fax,” although pronounced the same way) or Fluorescence Activated Cell Sorter machine identifies CD4 cells and directly measures what their proportion (percent) is of all your lymphocytes (white blood cells) when your blood was drawn. So, the CD4 *percent* is what the machine actually measures, and the *total* (or “absolute”) CD4 cell count is derived from multiplying the percentage of CD4 by the total lymphocyte count. That is why the differential (see above) from the CBC is necessary—in order to obtain your CD4 cell count.

Over time, the CD4 percent is a more stable measure of your immune system function because the total CD4 count is influenced by your white blood cell count at the moment your blood was drawn, a number that varies constantly. Nonetheless, by habit and tradition, health care providers have used the total CD4 cell count for key decisions, such as starting HIV meds or preventive therapy for opportunistic infections, like PCP (*Pneumocystis pneumonia*).

**3. HIV RNA PCR (HIV ribonucleic acid polymerase chain reaction), or “viral load.”** This key test tells us how much virus is in a milliliter (abbreviation: ml) of your blood, one-fifth of a teaspoon. *Note that it does not tell us how much HIV is in your entire body, where most of the virus is—in tissues, such as your lymph glands (lymph nodes).* Even though this test uses a tiny quantity of blood, it has proven to be a very good indicator of response to antiretroviral therapy.

There are two versions of the most commonly used test, the Roche assay, and both have established cut-off values for the upper limit of how much virus can be detected and the lower limit, which is referred to as “undetectable” virus. *Note that “undetectable” means the amount of HIV is less than the technical ability of the test to detect it and does not mean that HIV is not present.*

The Amplicor version of the viral load assay has a low end cut-off of “less than 400 copies/ml” of HIV RNA/ml and an upper limit of “greater than 750,000 copies/ml.” The

Ultrasensitive test has a low end cut-off of “less than 50 copies of HIV RNA/ml” and an upper limit of “greater than 75,000 copies/ml.” The significance of the difference between these two tests is that the Amplicor test is more accurate at higher viral loads and the Ultrasensitive test is more accurate at the low end of viral loads.

It is useful to do the Amplicor test when someone is first evaluated for HIV disease because it is valuable to know before starting treatment if the viral load is in the thousands, hundreds of thousands, or millions. Once someone is on HIV treatment and is doing well, it is more useful to use the Ultrasensitive test, given that the goal is to get the viral load as low as possible and this test is able to detect lower levels of virus in the blood.

There are other types of viral load tests, such as the branched DNA (bDNA) assay, that are sometimes used. There are various technologies but the measurement principles, with cut-offs for the upper and lower limits, are similar to what is described for the RNA PCR tests above.



## 4

### 4. Serum Chemistries—liver and kidney function tests.

**Liver Function Tests (LFTs):** These tests measure some key functions of the liver, a complex organ that does many important tasks in the body. The liver manufactures proteins that are essential to blood-clotting and to keeping fluid in your bloodstream instead of leaking out into your tissues and causing swelling (edema). The liver breaks down most environmental poisons (toxins) and drugs to rid the body of them. It also forms bile, which is important for digestion.

Amino aspartate transaminase (AST, formerly SGOT) and alanine aspartate transaminase (ALT, formerly SGPT) are key enzymes that indicate how well liver cells (hepatocytes) are functioning. The levels of an enzyme called alkaline phosphatase and a protein by-product called bilirubin indicate how well the production and excretion of bile is going. Albumin, a protein made in the liver, is critical for keeping fluid in the bloodstream and is an overall measure of nutritional status.

Liver function can be damaged by alcohol abuse, environmental toxins (including street drugs), viral infection of the liver (viral hepatitis) and a long list of diseases. Since people with HIV sometimes also have chronic hepatitis B or C, drink too much, or experience liver damage (hepatotoxicity) from medications, LFTs are important to monitor.

**Kidney (renal) function tests:** These tests measure how well your kidneys are doing their primary job, which is to rid the body of protein waste (blood urea nitrogen, or BUN) and regulate blood volume by filtering out the waste and extra water to form urine. The two main kidney function tests look at the level of waste as a way to measure how efficiently your kidneys are operating. These tests can provide clues that someone might have HIV-associated nephropathy (HIVAN) or kidney malfunction due to other causes, such as dehydration or drug toxicity.

Since some drugs are excreted from the body by the kidneys, dose adjustments need to be made when a person develops altered kidney function. Awareness of kidney dysfunction is also important when selecting an ARV regimen because some medications, like Viread, are not preferred for someone with underlying kidney disease.

Kidney function should be checked when someone enters HIV care. Thereafter, people at high risk of developing kidney disease (primarily African Americans and diabetics or people with a family history of diabetes) should have their kidney function checked at regular intervals. Routine checks are also recommended for people on ARV therapy.




## 5

**5. Syphilis blood test.** Syphilis, like HIV, is a sexually transmitted infection that may have no symptoms at all. If left untreated, it can cause—years later—significant disease and death due to damage to blood vessels and the brain.

There are a number of blood tests for syphilis (RPR, FTA, syphilis IgG), but the type of test is less important than the fact that everyone with HIV should have one upon entering HIV care and women who become pregnant should have one. After that, screening depends on risk—people who are at higher risk of exposure through unprotected sex, especially with multiple partners, may need to be screened regularly. Several outbreaks around the country among men who have sex with men have occurred over the past several years. Sex workers, incarcerated individuals, and people with other sexually transmitted infections are also at high risk.

**6. Tests for viral hepatitis.** Many HIV-positive people are also infected (“co-infected”) with chronic hepatitis B virus (HBV) and/or hepatitis C virus (HCV).



It is very important to find this out because, if left untreated, both conditions can ultimately lead to severe scarring of the liver (cirrhosis), liver failure, and liver cancer (hepatocellular carcinoma, or HCC for short).

Some HIV medicines are active against hepatitis B, so it is important to craft an ARV regimen that will adequately treat both HIV and HBV at the same time. Hepatitis C currently requires treatment with two drugs that do not control HIV, and this therapy can be pretty challenging. However, depending on virus type and other factors, treatment can be very effective.

In addition to HBV and HCV, it is also important to test your blood for proteins that are protective (called antibodies) to hepatitis A (HAV). There is no chronic form of hepatitis A, but if you already have chronic liver disease from hepatitis B or C, you can get much sicker from hepatitis A than someone who doesn't have HBV or HCV because you already have some liver damage. Since there are vaccines available for hepatitis A and B (but not, unfortunately, for hepatitis C), these should be offered to every HIV-positive person whose blood tests show no prior exposure to these viruses.

**7. Resistance tests (genotype and phenotype).** These tests tell us whether your virus is resistant to certain HIV drugs (in other words, the medication is not effective against your virus). Testing for transmitted resistance is now recommended before starting HIV meds, as up to 16% of people have a virus that is resistant to one or more antiretrovirals. These tests are also crucial for people who are not responding to their HIV therapy.

Both genotypes and phenotypes are done on a blood sample. Genotypes, which are simpler, faster, and cheaper to perform, identify changes in particular viral genes that are associated with reduced or no response to specific drugs. Phenotypes, which are more complicated, time-consuming, and expensive to perform, test how well your HIV grows in the presence of different concentrations of HIV drugs.

Genotypes may be more than adequate for early resistance because they look at how much resistance the virus has compared to virus with no resistance; phenotypes have some advantages for people with extensive resistance because they can indicate how well the virus responds to individual drugs. The phenotype results can be especially useful when there are no “new” drugs available to someone and the only option is a “salvage” regimen of drugs to which the virus is still susceptible.

In the most difficult cases, both tests add information of value. Cost can limit the availability of these tests, especially the phenotype.



#### ADDITIONAL TESTS, WHEN A CLOSER INSPECTION IS WARRANTED

**1. Testosterone level.** Among other key functions, testosterone is the hormone that drives sexual interest (libido) in both men and women, though normal levels for women are much lower than for men. Symptoms of low testosterone (hypogonadism) in men include: depression, lack of energy, reduced muscle mass, and decreased sex drive or arousal. Much less is known about women and testosterone, but low testosterone levels in women also cause decreased sex drive.

Hypogonadism seems to be common in HIV-positive men, though it is not known why. Testosterone levels in men normally decline with age, so the level has to be interpreted with your age in mind.

Testosterone replacement can be done by injection every few weeks or by gels or patches that are applied to the skin every morning. It is difficult to replace testosterone in women because the amount needed is so small, and current doses of various testosterone preparations are geared for treating men.

**2. Thyroid hormone level.** Low levels of thyroid hormone (hypothyroidism) are reasonably common in women—HIV-positive or not. Low thyroid levels can cause weight gain, lack of energy, depression, and skin changes. A thyroid stimulating hormone (TSH) level can screen for an underactive, as well as overactive, thyroid gland. Both underactive and overactive thyroid conditions can be treated.

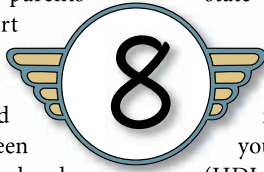
**3. DEXA (dual X-ray absorptometry) scan.** This scan tells us about the composition of the various body compartments—bone, fat, muscle—and is particularly useful in determining whether you have lost a modest amount (osteopenia) or too much (osteoporosis) of your bone mineral content. Osteopenia and osteoporosis weaken your bones and make them prone to breaking (fractures).

Bone mineral loss can occur in men with low testosterone levels and women who have stopped having periods (menopause). It can also run in families. This problem can largely be avoided with a good intake of calcium (at least 500 mg per day in dairy foods and leafy greens or as a supplement) and vitamin D (from exposure to sunshine, in fortified milk, or as a daily supplement).

It is important to do the kind of exercise that makes your muscles tug on your bones, such as resistance exercises that use weights or elastic bands. Walking briskly several times a week is also helpful because you are bearing your own weight, which helps keep your bones strong. In addition to calcium, vitamin D, and exercise, you can treat severe bone mineral loss with a medication you take once a week or once a month to help reverse bone loss.

Note: DEXA scans can also measure how much fat you have inside your body (visceral fat) and under your skin (subcutaneous fat), although this is more of a tool in studies of fat gain and loss (lipodystrophy) than a test used in the clinic to help with treatment of your HIV disease.

**8. Serum lipids.** Diet, exercise, cigarettes and your genetic heritage (the genes you inherited from your parents and ancestors) all influence your risk for heart disease. Since we now expect HIV-positive people to live a long time, we have to pay attention to the fact that both HIV itself and some of the medications used to treat it have been associated with abnormal lipid levels (cholesterol and triglycerides, which are fats in the blood). This makes it important to obtain fasting lipids when you first enter HIV care, and to have them repeated at least once a year. Repeating them more often will depend on whether they are normal or not to begin with and what other heart disease risks you have—are you overweight? Do you smoke? Do you have diabetes or high blood pressure? Do you exercise? Do you have a family history of high cholesterol or heart disease?



To be accurate, lipid testing must be done in the “fasted” state—no food (or drink, except water or diet soda or plain tea or black coffee—any drink without calories) for a minimum of eight hours, ideally 10 to 12. Fasting lipids include four separate measurements of different forms of fats that circulate in your blood: total cholesterol, high-density lipoprotein (HDL, or “good cholesterol”), low-density lipoprotein (LDL, or “bad cholesterol”), and triglycerides.

High levels of HDL protect you against heart disease caused by clogged arteries in your heart (atherosclerotic heart disease). Unfortunately, high levels of the other fats are associated with an increased risk for heart disease. Lipid levels can be lowered with lifestyle changes, but some people may also have to take lipid-lowering drugs in addition to a diet change and other interventions.

**9. Pap smear.** A Pap smear involves scraping cells from the cervix or anus (usually with a tiny cotton swab), preparing them on a slide, and viewing them through a microscope. Every HIV-negative woman should be screened once a year for cell changes on the cervix that could lead to cervical cancer. Depending on CD4 count and other factors, women who are HIV-positive should be screened twice a year (every six months) for cervical cancer.

Cervical cancer is caused by infection with certain strains of human papillomavirus (HPV). Cervical cancer is a real threat to HIV-positive women, especially at lower CD4 counts, and became part of the case definition of AIDS in 1993. If caught early, it can be cured.

Anal Pap smears are still not standard of care due to limitations of the test and because an expert is needed to accurately analyze the results. The wealth of data that exists for cervical Pap smears does not exist for anal Paps, so questions remain about its reliability and predictability as a screening tool. In some centers, anal Paps have been an effective way to screen for anal carcinoma, but many centers lack health care providers and pathologists (the doctors who interpret Pap smears) who can perform this test reliably.

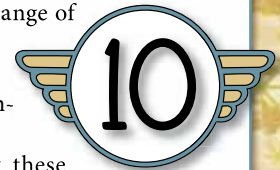
This test was developed initially for men who have sex with men, thought to be susceptible to anal carcinoma because of sexually transmitted HPV infection. However, women can also benefit from such a test, even if they have not had anal intercourse.



**10. Screening tests for cancer.** Now that HIV-positive people have the prospect of living out a normal lifespan, it is important to provide cancer-screening tests because most cancers are age-related. Also, there is some evidence that people who are HIV-positive may be at higher risk for a broader range of cancers than the ones that have long been HIV-associated, like Kaposi's sarcoma and B cell lymphoma.

The guidelines for performing these screening tests are the same as those for HIV-negative individuals.

- For men aged 40 and older: an annual prostate-specific antigen (PSA) blood test to look for prostate cancer
- For women aged 40 and older: a baseline mammogram (type of x-ray) to detect breast cancer, with subsequent mammograms based on age and family history
- For all people aged 50 and older: a baseline and then subsequent colonoscopy to detect colon cancer
- For smokers: QUIT! A chest X-ray may be prudent for smokers, but there is no clear interval for subsequent screening. ✚



*Judith Feinberg, MD, is a clinician and Professor of Medicine at the University of Cincinnati, where she is also the Director of the AIDS Clinical Trials Unit. Dr. Feinberg is an American Academy of HIV Medicine (AAHIVM)-credentialed HIV Specialist.*

# Helping Your Antiretrovirals Help You

## THINGS TO CONSIDER WHEN CHOOSING WHAT GOES IN THE TANK

BY MELISSA NGO, PHARM D

**O**verwhelmed! That is the first word that comes to my mind when I think about an HIV patient who is about to begin antiretroviral therapy for the first time. I think of all the information being sent the way of someone starting therapy—by physicians, nurses, patient educators, and pharmacists. All of this information is provided in order to help with the start of this important journey, but it can definitely be overwhelming.

As a pharmacist who has worked in an HIV clinic, an outpatient pharmacy, and a medication management mail-order pharmacy, I have seen patients from a variety of perspectives. In each of these different surroundings, some things have remained consistent—patients have to deal with a myriad of things involved in starting (or switching) antiretroviral therapy, and patients do better if they understand how critical adherence is and come to terms with it. I suggest that anyone thinking about beginning a new medication regimen feel really ready for this big step before taking it.

Rarely is it imperative that antiretroviral treatment be started on an urgent basis. Therefore, you can be open with your physician if you are not yet prepared to begin therapy. Also, before beginning treatment, learn how the medications you'll be taking work in your body and the side effects they may cause. Make sure you are committed to working through complications or problems if they arise.



There are so many different opinions and suggestions about when to start antiretroviral therapy that it is hard to determine the right time for an individual person. Even though things like CD4 counts and viral loads are important factors in making this decision, the most important determinant is that the individual person is ready to start and adhere to therapy.

Adherence to an antiretroviral regimen is extremely important. If a patient starts therapy but does not take it consistently every day, or decides to stop after beginning a regimen, there is a chance of developing medication resistance. However, this does not mean that starting a particular regimen means you can never change it.

If a treatment is not working due to side effects, dosing schedule, or medication intolerance, there is always the option to change to a different combination of medications. It is *crucial* that the physician be informed and involved with switching therapy. Having an expert help with the change will decrease the potential for building resistance to medications.

### FINDING A REGIMEN THAT SUITS YOU AND YOUR LIFESTYLE

Are you ready to start your antiretroviral therapy? If so, there are a few things to keep in mind as you and your physician begin to choose a treatment that is right for you.

1. It is important to understand the goals and benefits of therapy. Antiretroviral medications are a cornerstone in the

treatment of HIV-positive patients because of their ability to restore and maintain immune function, prevent illness and death, and improve quality of life. The more you understand about medication therapy, the more you will be able to make informed decisions.

2. Before starting therapy, it is a good idea to have baseline laboratory tests performed. These tests will help you and your provider understand where your body's pre-antiretroviral therapy starting point is. Knowing this starting point will help your physician understand your current health status with respect to what the HIV is doing and anything else, unrelated to HIV, that might be going on.

Lab tests will also guide your physician in choosing appropriate treatment. For example, if lab results indicate highly elevated lipids prior to starting therapy, your physician may want to avoid most of the protease inhibitor class, or address the elevated lipids upon initiating therapy.

3. Think about what will work for you in your life. There are many combinations of drugs to choose from when starting therapy if you are "treatment naïve"—starting your first ARV regimen ever. Things to consider when choosing a specific regimen, besides pre-treatment lab work, include:

- total number of pills per day
- dosing frequency
- food considerations
- drug interactions
- adverse medication effects and
- the potency of the regimen itself.

4. Whenever possible, make sure your choice provides a good "Plan B" option if some medication resistance emerges. This

is called drug sequencing. You and your physician will likely choose a regimen that consists of medications in at least two different antiretroviral drug classes while also sparing as many other classes of drugs as possible for future use. These other drug classes will be reserved for use in the event that the virus becomes resistant to a specific class of drugs.

Your physician may do some drug resistance testing before you begin ARV therapy to determine if there are any medications to which your virus is already resistant. However, this test is often reserved for patients who are not responding to their current regimen ("treatment-experienced" patients).

With so many things to consider, you may wonder how you or your physician actually decides which combination of drugs to use. The good news is that there are guidelines to help with the decision-making process. It is important to remember, however, that one, guidelines change over time as new medications become available and more information is learned about existing medications, and two, these are just guidelines. Each individual person must find the regimen that will work best...for that person.

**MAKING IT WORK**

Once you start your new antiretroviral therapy, you may begin to realize that you are having trouble adhering to your regimen for one reason or another. If that happens, there are a variety of strategies that may help you.

From my experience, patients find pill boxes very helpful for organizing their medications and as a way to remember if they have taken them. Calendars can also be useful because each day can be marked to indicate that a dose was taken. Pill boxes and calendars are both inexpensive tools that can be very helpful. The

**CURRENT INFORMATION FROM THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (DHHS) PANEL ON ANTIRETROVIRAL GUIDELINES FOR ADULTS AND ADOLESCENTS (UPDATED OCTOBER 10, 2006) FOR TREATMENT-NAÏVE INDIVIDUALS IS AS FOLLOWS:**

Clinicians are recommended to construct a regimen by choosing one component from Column A plus one component from Column B

	COLUMN A		COLUMN B
	NNRTI	PI	2-NRTI
Preferred (alphabetical order)	Efavirenz <sup>1</sup>	Atazanavir + ritonavir Fosamprenavir + ritonavir (twice daily) Lopinavir/ritonavir (twice daily)	Tenofovir/emtricitabine <sup>3</sup> Zidovudine/lamivudine <sup>3</sup>
Alternative (alphabetical order)	Nevirapine <sup>2</sup>	Atazanavir <sup>4</sup> (unboosted) Fosamprenavir (unboosted) Fosamprenavir + ritonavir once daily Lopinavir/ritonavir once daily	Abacavir/lamivudine <sup>3</sup> Didanosine + lamivudine <sup>3</sup>

<sup>1</sup> Except during first trimester of pregnancy or in women with high pregnancy potential

<sup>2</sup> Nevirapine should not be initiated in women with CD4+ T-cell count greater than 250 cells/mm<sup>3</sup> or in men with CD4+ T-cell count greater than 400 cells/mm<sup>3</sup>

<sup>3</sup> Emtricitabine and lamivudine are interchangeable

<sup>4</sup> Atazanavir must be boosted with ritonavir if used in combination with tenofovir.

*Editor's note: Above drug names are generic. Please refer to the Positively Aware January/February HIV Drug Guide for brand names, or visit [www.tpan.com](http://www.tpan.com).*

*For a full version of the DHHS guidelines, visit [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov).*

good news is that adherence has gotten easier as new antiretroviral therapies have been developed that require fewer pills and fewer doses throughout the day.

#### **SORTING OUT DRUG SIDE EFFECTS**

Antiretroviral therapy has come a long way over the past decade. However, the longer medications are on the market, the more we find out about the side effects they can cause. It is unfortunate, but many of these therapies have a lot of possible short-term and long-term side effects.

It is important to remember that every medication has a list of possible side effects associated with it. That does not mean that everyone taking a particular medication will develop every side effect on the list, or any of them, for that matter. It is a good idea to understand the potential side effects associated with each of your medications, though, so you'll know what to look for if you do experience any problems after starting therapy.

If you have any side effects, or if any side effects you are experiencing become intolerable, make sure to discuss them with your physician. I have seen too many patients who have started therapy, experienced a side effect that they struggled with, then stopped therapy on their own without ever letting the doctor know there was a problem. Patients who stop therapy without speaking with the physician risk developing medication resistance because some medications need to be stopped in a particular order in order to avoid resistance.

Antiretroviral medications can have side effects that are common for the class they are in (e.g., protease inhibitors and gut distress), but there are also side effects that are specific to each medication. It would be impossible to list every side effect for every medication in this article, and probably boring. The point is this: when you start a medication, take time to learn about the side effects from your physician, pharmacist, or written information on that specific medication.

As a class, nucleoside reverse transcriptase inhibitors or NRTIs (drugs like lamivudine, abacavir, and zidovudine) all have the potential to cause some serious side effects. NRTIs can cause pancreatitis, lactic acidosis (a dangerous build-up of acid in the blood), and an enlarged, fatty liver.

Non-nucleoside reverse transcriptase inhibitors or NNRTIs (drugs like efavirenz and nevirapine) share the potential side effects of serious rash, nausea, and vomiting.

The class of protease inhibitors or PIs (drugs like ritonavir, lopinavir/ritonavir, atazanavir, and fosamprenavir) can also cause many side effects. Some of the short-term side effects include diarrhea and nausea or vomiting. Possible long-term side effects include increased cholesterol and triglyceride levels, lipodystrophy (body shape changes), cardiovascular risks, and new or worsening diabetes.

The fusion inhibitor class currently has only one medication in it—enfuvirtide. The most common side effect is an injection site reaction (ISR) that occurs to some extent in all patients who use it.

It would be easy to think you could expect the side effects common to a class of ARV from any drug in the class, but it's not that simple. Atazanavir, for example, does not share the same lipid-raising profile of its classmates. Likewise, abacavir has the potential for a hypersensitivity reaction (HSR) that the other NRTIs do not, and it appears to be less toxic on the cellular level than some of the others in its class. Similarly, the central nervous system effects (like

dizziness, vivid dreaming, and mood changes) associated with efavirenz do not extend to the other drugs in the NNRTI class.

#### **MANAGING SIDE EFFECTS**

Managing side effects from antiretroviral therapy can sometimes be a difficult task. However, it's important to manage side effects not only because it may make you feel better, but because side effects are a leading cause of treatment non-adherence.

It is possible that a side effect could occur that cannot be managed with additional medications or other supportive measures, which could become intolerable. If that happens, it usually means discontinuing the drug(s) causing the problem and likely making a substitution, with assistance and supervision of your physician.

Some side effects occur with the start of therapy, but will resolve after a couple weeks of continued use. There are other side effects, however, that may need to be managed for the duration of the therapy. If that happens, there are steps that you can take to reduce some of the more common ones.

- Nausea and vomiting often resolve without intervention within a few weeks. However, there are things that can be done to help manage these troublesome symptoms. Eating bland foods and small, frequent meals may help. In situations of severe nausea and vomiting, medications like prochlorperazine and ondansetron can also be helpful.
- Diarrhea may seem like it's just a nuisance, but it can be serious if it leads to dehydration. Remember, if you get episodes of diarrhea, it is important to drink lots of fluids in order to stay hydrated. Avoiding caffeinated beverages, alcohol, spicy foods, fried foods, and dairy products may help with diarrhea. Medications like loperamide and diphenoxylate/atropine may also help, as well as psyllium powder and the amino acid L-glutamine.
- Intestinal gas is sometimes produced from certain foods you eat, like beans and vegetable skins. Your intestines need these kinds of fiber, though, so you can talk to your doctor about adding an enzyme called alpha-galactosidase and/or a drug called simethicone. Both are available in over-the-counter products like Beano (alpha-galactosidase) and Gas-X (simethicone). These can help your stomach digest "roughage" better.
- Peripheral neuropathy is commonly caused by some NRTIs, like ddI and d4T. Medications such as ibuprofen and topical creams that contain methyl salicylate may help minor symptoms. For more moderate to severe symptoms, medications like gabapentin or amitriptyline sometimes help.
- Muscle pain may be controlled with medications like acetaminophen and ibuprofen.

Some side effects may only be found with routine lab work. Depending on the severity, these side effects may be managed under physician supervision with either concurrent drug therapy or a change in antiretroviral therapy. Your physician should be monitoring for things such as:

- decreased renal or liver function,
- increased cholesterol or triglyceride levels,
- changes in blood glucose levels, and
- changes in red and/or white blood cell counts.

Please discuss all side effects with your physician before trying to treat them yourself. Sometimes there may be underlying causes of the symptoms that need further evaluation. Also, possible drug

interactions between your ARVs and other medications you might be taking need to be considered, even if you're just using a new over-the-counter medication.

#### DRUG INTERACTIONS

The topic of drug interactions is extensive and could comprise an entire magazine issue on its own. Every medication, even ones you think are harmless, may cause drug interactions with your current regimen of antiretrovirals.

Here's a common example that I have seen in the pharmacy. A patient experiences heartburn and comes into the pharmacy to purchase Prilosec OTC, the strongest over-the-counter medication for heartburn. The patient just happens to be on ARV therapy that includes atazanavir. The Prilosec OTC may treat the heartburn, but what the patient does not realize is that a simple item like Prilosec OTC decreases the absorption of the atazanavir. This reduction in atazanavir levels in your blood could lead to the development of resistance to atazanavir.

The above example hopefully illustrates the importance of discussing any new medication with your HIV physician or pharmacist. This includes, by the way, any medication started by a physician *other than* your HIV physician. Providers who do not practice HIV medicine often have little or no HIV-specific knowledge—so be sure to discuss any new medications with your HIV provider.

There is a constant flow of new information about ARVs and how they work, which makes it especially important to discuss all new medications with your HIV provider. Hopefully, you feel like you can be honest with your doctor about what you take and your doctor knows what to do with the information.

#### NEW DRUGS AND COMBINATIONS

For the first time in a while, there are several promising medications in the pipeline of the antiretroviral world and a few that are new to the market. Make sure your doctor is aware of and knowledgeable about newly approved drugs and those in development. This is especially important if the existing treatments are not working for you.

Following are some examples of newly approved drugs and drugs that are currently being studied.

#### APPROVED:

- Atripla, a combination of efavirenz, tenofovir, and emtricitabine, was approved by the FDA on July 12, 2006. It contains no new medications but it is exciting because it consists of only one pill once daily—the simplest regimen yet.
- Prezista (darunavir), a new protease inhibitor indicated for people with PI-resistant virus, was approved in June by the FDA. It is taken twice a day and, like most PIs, is boosted by ritonavir. The buzz is that it is supposed to have fewer side effects than currently used PIs, with less potential for resistance.

#### IN LAST STAGES OF DEVELOPMENT:

- Etravirine is an NNRTI that has shown activity against NNRTI-resistant virus. It is being studied using twice-daily dosing.
- Maraviroc is an entry inhibitor (it blocks the CCR5 receptor on the CD4 cell) that's causing excitement because it represents a new class of antiretrovirals. It adds another option

to existing ARV therapy, making it of potential value to people who are treatment experienced. It will likely be taken twice a day with other ARVs.

- MK-0518 is likely to be the first in a whole new class of ARVs—integrase inhibitors. It is being studied as a twice-daily drug to be taken with other ARVs. The data so far have been very promising, especially for people who are resistant to currently available medications.

#### TIPS:

- Go to an HIV specialist for treatment of your HIV. Make sure it is someone with whom you feel comfortable communicating your ideas, thoughts, and concerns. It should also be someone who is on top of the current research and will work to make sure you have access to all available options.
- Make sure you are ready to start therapy before actually starting therapy. Try to build a level of comfort with it.
- Always check with your HIV physician or pharmacist before adding anything new to your regimen, even over the counter medications or nutritional supplements.
- Never stop therapy without discussing it with your HIV physician first. ☒

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#### RESOURCES:

##### AIDS COMMUNITY RESEARCH INITIATIVE OF AMERICA

In addition to a quarterly treatment newsletter and information on current clinical trials, the AIDS Community Research Initiative of America (ACRIA) offers useful publications on specific topics that can be read on-line or in hard copy. Some examples: *Understanding Your Lab Results*, *Treatment Issues for Women*, and *Managing Drug Side Effects*. Visit [www.acria.org](http://www.acria.org).

##### AIDSINFO

An HIV/AIDS site from the National Institutes of Health (NIH). It contains links to a variety of information, including treatment guidelines, clinical trials, and fact sheets. Call 1-800-HIV-0440 (448-0440). TTY 1-800-480-3739. Outside the U.S. call 301-519-0459. Visit [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov).

##### THEBODY.COM

The Body is a collection of a huge variety of HIV information from a multitude of sources. It is a virtual “warehouse” of HIV information, which it offers in all kinds of formats—forums, fact sheets, articles, interviews, conference coverage... to name a few. Visit [www.thebody.com](http://www.thebody.com).

# Can It Get Even Better Than This?

You don't need to trade in for a newer model—you can live longer and better... while controlling HIV

by Charlie Smigelski, RD



**A**t a conference recently, I was having supper with a few of the organizers, who have been living with HIV for over 15 years. I had lectured on nutrition at the meeting, so the conversation drifted to their own concerns. We were talking about having high cholesterol and a “touch of diabetes,” problems that ran in the family for one guy. The other guy had 25 pounds of middle-age gut he kept meaning to do something about. Both mentioned wanting to have a little more energy.

These two were typical of many people at this phase of the disease: some side effects, but not as bad as before, and some body shape changes that were maybe caused by HIV or by HAART (highly active anti-retroviral therapy) or by being 40-something. As we talked about diet and nutrition ideas for them, I recognized a familiar pattern: what they didn't know about good nutrition for long-run health mirrors the situation for most people entering or in middle age; what they didn't know about nutrition for chronic infection and for people on HAART was slowly brewing the fatigue, plus heart disease and diabetes risks. I recognized these as exactly the topics in many medical visits for people these days.

I encouraged my dinner companions to spend some time and energy getting in better nutritional and physical shape. Today, as medicines are doing pretty well with managing HIV, it's time to step back and take stock of the whole person—body, energy, and future metabolic risks. My message for them (and anyone in a similar

situation): don't just live with side effects of meds, even though they may be less than before. You might be in okay-enough shape, but imagine having it be even a little better.

*What modest changes would it take to feel a little stronger, be in a little better shape, and prevent other complications down the road?*

**You are what you eat. Think about feeding your body parts just a little better.**

Tonight while you sleep, you're repairing brain cells, muscle cells, nerve cells, liver cells, and skin cells. Will your system be sorting through a minefield of groceries to find the right reconstruction materials? Will happy serotonin messages hop through brain cell membranes made of nice slick fish oils, or will the neurotransmitter have to slog through sludgy beef and cheese fat?

Last year, endocrinologist Steve Grinspoon found fatty livers in 50% of people recruited for an HIV metabolism study. A fatty liver is step one in giving people “a touch of diabetes” (especially true for people co-infected with hepatitis C and HIV). Excess weight, antiretrovirals, and oxidative stress of infection play a role in the fat being there, but dietary fats and excess sugar can amplify the problem.

Think about it: what kind of grease was your last serving of French fries cooked in? What kind of semi-plastic shortening was in the muffin or cookies you snacked on yesterday?

The ideal food plan is a caveperson-style diet. It's a chunk of protein for breakfast, and more for lunch and supper. It's careful about fat. For the caveperson, there was only lean protein—fish, mussels, scallops, birds, and maybe deer or antelope. The only other fat to be found back then came from nuts and seeds. The omega 3 oils in fish, plus the oils in nuts and seeds, are the fat your genes are most comfortable with. Corn and vegetable oils are new creations.

The Grinspoon group that reported on the fatty livers also found that people eating more polyunsaturated fats (found in vegetable oils, like corn and safflower) experienced more lipodystrophy. Remember: nuts, seeds and fish oils know how to travel in your system, keeping your face filled out instead of wasting and your arms and legs from looking too veiny/vascular.

For the caveperson, melons, fruits and berries—plus a lot of leaves and shoots—were major fuel sources. Grains hadn't been invented yet, so you would have eaten two bags of spinach leaves to get the 200 calories that Lender stuffs in your bagel. As you can imagine, there is a whole lot more T-cell support in the leaves, blueberries and strawberries than in flour and water, which makes school-kid paste...and bagels.

When you're looking for some starches for dinner, give peas a chance. Dig some tubers, like potatoes. Put some pintos, black beans or lentils on your plate, daily. Okay, after all this, you get some dark chocolate, or milk and a macaroon, for dessert.

The simple truth is this: a higher protein diet with extra big servings of fruit and vegetables, careful selection of fats, and some attention to limiting junk carbs (those muffins and cookies) goes a long way to preventing or reversing lipodystrophy. It also keeps heart disease away.

*What kind of metabolic and physiologic shape are you in?*

**Perform a self-scan, top to bottom, and see what could get buffed up a bit.**

**Hormones** direct your metabolism. How are yours? Be sure your testosterone levels are okay. It's not just about libido—testosterone matters to bone and muscle strength, sugar and cholesterol metabolism, and better mood. When testosterone runs low, the body experiences this condition as something stressful and releases more of a particular inflammatory signal. This messes up insulin signaling and disrupts fat cell refilling. Know what your total and free testosterone levels are. If they are low, fix them. This goes for both men and women.

*Ed. note: There is limited data available regarding HIV-positive women and testosterone, but it is known that low testosterone levels can occur. Some physicians replace testosterone in women using patches or gels/creams, though it can be challenging to find a dose low enough to avoid masculinizing side effects like excess hair and acne - careful monitoring is required. There have been promising studies on the impact of testosterone replacement in women to treat muscle wasting; research continues on the impact of testosterone on bones, muscles and energy.*

**Intestine cells** struggle. All stretched out, intestines cover an area the size of a tennis court. Gut cells are replaced every three to four days, a huge amount of work for the body. HIV changes their shape and size, reducing their ability to absorb nutrients. Antiviral medicines, like protease inhibitors, often irritate gut cells.

When something is not right in this gut cell system, it's quite a strain on the body.

Gut cells will send out distress signals, but these can distort metabolism, again making it hard to keep fat cells filled up in the right places, and making it hard to maintain weight.

View your intestines as an ecosystem. There are about 4 pounds of beneficial bacteria that live in the intestine. They depend on fruit fibers, like the pectin of apples and bananas, for their nutrition—what they would get from the three to four doses of fruit a day in your cavewoman diet. These good bugs make the amino acids and fats that are “repair groceries” for the intestine surface. If they are not doing their job well enough, the back-up amino acid supply for gut repair, L-glutamine, gets pulled from the supply in the muscles. In this way, gut distress and repair problems can affect the muscles all over the body.

In your scan of body systems, think about how your intestines are doing. If you are having diarrhea a few times a week, don't just take anti-diarrhea pills. They only treat the symptom. Behind the scenes, something is not right in the repair process. Use good nutrition as the authentic solution. Eat enough fruit, and then learn about acidophilus/probiotic blends of supplements and L-glutamine to support your gut.

Do you get the diarrhea that happens about one hour after a meal, the “uh-oh, I gotta find a bathroom in about 12 seconds” kind of urge? This is about digestion problems, not about gut cell repair. There is a pH (acidity) problem in your intestines. Protease inhibitors can keep the intestines a little too acidic, so fat digestion is not complete enough. Unabsorbed fat turns to soap, and—bam!—you get the hurry call.

There is a pancreatic enzyme called Pancrecarb (available by prescription) that can help with digestion. Unlike other digestive enzyme supplements, it contains bicarbonate, which helps restore the natural conditions necessary for digestion in the upper intestine. I get e-mails from people all over the country who tell me that the combination of one teaspoon of L-glutamine powder

once or twice a day plus Pancrecarb, taken with meals, has stopped years of diarrhea within a day or two of taking them.

Know what you personally have to do to be sure your intestinal system is in great shape. Your whole body will be happier for it.

**Mitochondria** are the power plants of cells—they convert nutrients into energy. They are not something you can scan, but your blood fats—triglycerides and cholesterol—can give you a good idea of mitochondrial functional status.

Okay, let's presume that your diet is reasonable and your health status is alright. You eat good foods most of the time, and desserts are modest. T-cells are stable and above, let's say, 100; viral load is less than 20,000. Let's also say you don't eat over-the-top amounts of grease and sugar and you don't have fevers and wasting, which can also raise blood triglyceride (fat) levels.

You have probably heard the term “mitochondrial toxicity,” especially with respect to drugs like d4T and ddI, which have been shown to cause more mitochondrial damage than some other antiretrovirals. When mitochondria are damaged, fat you eat isn't burned up for energy completely enough and it accumulates in cells. Switching to a less toxic drug can reduce the mitochondrial damage, but repair is slow and fat metabolism is sluggish, and so, are you.

Cells clogged with fat are irritated and release a stress signal that messes up sugar metabolism, including insulin activation. A chronic infection like HIV (or HCV) generates many stray electrons (“those darned free radicals,” as Dr. Judy Shabert has called them), which means more mitochondrial stress.

For someone with HIV, a blood triglyceride (think: grease) level above 150 suggests mitochondrial energy-processing trouble. Triglycerides travel with a cholesterol coating, so blood cholesterol levels rise, as well. Unfortunately, the level of “good cholesterol

ol,” HDL (high density lipoprotein), doesn’t rise amid the irritation—it drops.

It is common to treat the high lipids with a statin drug like Lipitor, or a fibrate like Tricor, but these are seldom effective enough. Medical groups at the VA and at Baylor University report that 75–80% of their HIV patients with hyperlipidemia fail to reach proper cholesterol and triglyceride lipid levels using standard drug treatments. While statins and fibrates lower blood fats by blocking an enzyme that’s needed to make cholesterol, nutrition repairs the basic cellular problems of mitochondrial distress, poor fat-burning, and deranged sugar metabolism.

#### BE NICE TO YOUR MITOCHONDRIA

When it comes to mitochondria, what my recent dinner friends and you need to know is how to help liver and muscle mitochondria restore fat-burning and energy-making ability.

First, taking some extra antioxidants, like 1,000 mg of vitamin C and 600 IU of vitamin E each day, can go a long way to repairing mitochondria. Next, taking 1 to 1.5 grams a day of the amino acid L-carnitine for a month or two can generally lead to a drop in triglyceride levels by at least 25%. Then, taking 3 grams a day of omega 3 fats (fish oils) tells the liver cells to burn off some stray fat in peroxisomes, alternative energy-making units in cells.

The combination of caveperson diet, two to three antioxidant vitamin pills per day, some fish oils, and L-carnitine for a few months offers the prospect of radical improvement in blood fats. One of my patients on Kaletra and Combivir, plus gemfibrozil to lower lipids, had his triglycerides drop from 1800 to 400 in four weeks after he adopted this nutrition regimen. Another patient, on a PI-only regimen of Kaletra and Fortovase and 10 mg of Lipitor, had a cholesterol of 278 and triglycerides of 1,400. Seven weeks into the caveperson diet plus two antioxidant-with-B-complex vitamin pills, 3 grams of fish oil and 1 gram

#### HOW CLOSE IS YOUR DIET TO THIS LIST each day?

1. Protein foods: breakfast, lunch, and dinner
2. Fruit servings: 3-4 times per day
3. Vegetables: at least 2 cups a day
4. Carbohydrates that digest slowly (black beans, lentils, peas, corn)
5. A handful or two of nuts and seeds
6. Zero fats that harm your body (cream, butter, stick margarine, hydrogenated shortening)

of L-carnitine, he e-mailed me to report his cholesterol was down to 172 and his triglycerides were at 166. He had also gotten back to a walking program of three to four times a week.

The supplement regimen is not forever. Taking some good vitamins to support both CD4 and CD8 T-cells is fundamental. This can cost as little as \$12 for a six-month supply (e.g. Trader Joe’s Vitamin Crusade antioxidant formula). Buyers clubs (e.g., Boston, Houston and New York Buyers Clubs) have more potent combinations that cost more but include more immune-supportive trace minerals, like selenium and magnesium. (Visit [www.bostonbuyersclub.com](http://www.bostonbuyersclub.com), [www.houstonbuyersclub.com](http://www.houstonbuyersclub.com), and [www.newyorkbuyersclub.org](http://www.newyorkbuyersclub.org).)

You might take less of the other supplements. Salmon for lunch and supper a few days a week may replace fish oil pills. A lot of people find the L-carnitine gives them energy, so they keep taking some. Some people take 100 mg of coenzyme Q10 for a few weeks at a time, because they feel it also gives them added energy. These extra supplement items each cost \$10-\$15 a month, which adds up. Save money; use them when you need them.

*Where do you go from here?*

**Start by getting in touch with the way you eat and live.**

The news from HIV research and care centers is that being on HAART increases the risk of heart disease. Fat carried in the gut area contributes to elevated cholesterol and insulin resistance, a contributor to diabetes. High blood fat is part of it; irritations from medicines play a part, too. Lifestyle stuff—excess weight, cigarette smoking, lack of exercise—also contributes.

Step back and take a look at how well you are really eating these days. Maybe write down everything you eat for 3 days, including one weekend day, and size it up against the checklist here. The goal is to get as close to this list as possible so your body works as well as possible and you feel good...or even better.

In making changes in your lifestyle, discover the benefit of some extra focus on diet and nutritional supplements. There are small steps, like my dinner companions and I sharing one dessert as a step toward weight management, and bigger ones, like trying a protein-fruit-nut breakfast for a few weeks. Explore what high quality vitamins or other supplements might do for your energy levels.

The bottom line is that there are many steps you can take to help control the effects of HIV disease, antiretrovirals, and aging. The important thing is to start. ☞

References available at [www.tpan.com](http://www.tpan.com).

*Charlie Smigelski is a Registered Dietitian who has been with Fenway Community Health Center, one of Boston’s primary HIV treatment and research centers, for 14 years. His special emphasis is on how diet and supplements can reduce or reverse side effects of HIV and HAART, and helping people live more comfortably with their medical regimens. He is the author of Eat Up! Nutrition Advice and Food Ideas For People With HIV and AIDS.*

# DON'T FORGET YOUR HEAD

BEFORE YOU GET BEHIND THE WHEEL, MAKE  
SURE YOU ARE IN FULL CONTROL

BY TONIA POTEAT, PA-C

**V**iral load and CD4 counts are such useful indicators of viral activity and immune function that there is always the danger that the measure of “how things are going” begins and ends with those two tests. While these and other lab values are undeniably important, we can't forget that the motivation for taking care of ourselves resides in our heads, not our bloodstreams. Below are just a few of the psychological issues that can affect the well-being of people with HIV.

## **DEPRESSION: THE SLIPPERY SLOPE**

Marilyn has found it harder and harder to wake up in the morning and has been going to bed earlier and earlier each night. She used to look forward to walking the dog in the mornings and attending her weekly women's group. Lately, she feels sluggish all day and no longer wants to do anything. She had to change her HIV medications a few weeks ago and attributes her feelings to side effects from the new medications. In fact, she's beginning to wonder if it's even worth it to keep taking her medications.

Marilyn's story is common. While it is true that some of what she feels could be due to her new medications, it's more likely that Marilyn is suffering from the most common mental health problem among people with HIV—depression. Symptoms of depression can overlap with medication side effects, so depression can be missed both by the person with symptoms and the health care provider.

Fortunately, depression is a very treatable condition. It's quite likely that Marilyn can get back to her old self, especially if she addresses her symptoms early, reaches out for care and gets an experienced provider who listens to her. The danger is that, because of the way depression affects thinking, Marilyn will begin to accept her new reality as “just the way it is” and won't think there's anything that can help. She will also have to fight the sense of shame or failure that many people feel when they are depressed, which prevents them from getting the help they need to get better.

Treating depression is very important for both your mental and physical health. Untreated depression has been associated with

faster progression of HIV disease, poor adherence to medications, high-risk sexual behavior, drug use, and even death.

If you experience five or more of these symptoms for at least two weeks, you should talk with your health care provider about depression.

1. Sadness, hopelessness
2. Decreased interest or pleasure in activities
3. Sleeping too much or sleeping too little
4. Appetite changes with weight gain or loss
5. Loss of energy
6. Feelings of worthlessness or guilt
7. Decreased ability to concentrate
8. Psychomotor agitation (pacing, wringing hands, hair twirling) or psychomotor retardation (slowing down of thoughts, movement, or speech)
9. Recurrent thoughts of death or suicide

There are many effective treatments for depression, including several different classes of antidepressant medications and various types of counseling and psychotherapy. Most mental health providers advise treatment with a combination of psychotherapy and medications for at least six months.

## **ANXIETY: THE MONKEY OF THE MIND**

Anxiety frequently accompanies depression. However, anxiety can occur alone. Anxiety can cause psychological symptoms like excessive worry or fear, as well as physiological symptoms such as breathing problems, chest palpitations, muscle tension, nausea, headache, and dizziness.

Getting an AIDS diagnosis, changing antiretroviral medications, or other serious changes in health status are common triggers for anxiety. Just like depression, treatment for anxiety usually includes a combination of medications and psychological interventions, such as psychotherapy and/or cognitive-behavioral therapy.



#### **ADDICTION: THE LINE BETWEEN USING AND ABUSING**

While some people use alcohol or recreational drugs to help them relax or to have fun, it can be difficult to tell when “use” has become “abuse” or “addiction.” The DSM (a reference book of psychiatric definitions called the Diagnostic and Statistical Manual of Mental Disorders) defines addiction as a “maladaptive pattern of substance use leading to significant distress or impairment.”

So, how do you know when use isn’t really helping you and may be hurting you? A list of four questions, commonly called CAGE (Cut, Annoyed, Guilty, Eye-opener) questions, can be very helpful in determining if you have an alcohol or drug problem. If you answer “yes” to any of these questions, you may have a problem with alcohol or drugs.

1. Have you ever felt like you should **cut** down on your drinking or drug use?
2. Have you been **annoyed** by people criticizing your drinking or drug use?
3. Have you felt bad or **guilty** about your drinking or drug use?
4. Have you ever had a drink or used drugs early in the morning to steady your nerves or get rid of a hangover (**eye-opener**)?

While the short-term psychological affects of drug use may be obvious, long-term mental and physical consequences can be more subtle. For example, long-term use of a drug as simple as marijuana can lead to impaired brain function. Methamphetamines (crystal meth, crank, etc.) have been shown to have effects on the brain that last for months after the drug was last used. Physical problems like strokes and heart attacks are frequently seen after use of stimulants like cocaine. The short and long-term effects of each drug are different, so it’s important to know as much as you can about any substance you put in your body.

If you use drugs and do not want to quit, harm reduction programs may be able to help you stay as healthy as possible by providing information and equipment for safer use. If you use drugs and want to quit, programs like Alcoholics Anonymous and therapeutic communities use an abstinence-based approach to dealing with

drug use problems, and can provide you with a supportive environment to help you quit.

Depression, anxiety, and addiction are just a few of the mental health issues that people with HIV may confront. Remember that it’s important to pay as much attention to your mental health as you do to your physical health and address any concerns early. Living well with HIV means taking care of your whole self—body and mind. ☕

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#### **RESOURCES:**

**Psychology Information Online** is a resource for information about a variety of psychological issues and conditions, including depression. Visit [www.psychologyinfo.com/depression](http://www.psychologyinfo.com/depression).

**Anxiety Disorders Association of America** provides an overview of anxiety disorders, as well as information about treatment and statistics. Visit [www.adaa.org](http://www.adaa.org).

**The Harm Reduction Coalition (HRC)** is committed to reducing drug-related harm among individuals and communities by initiating and promoting local, regional, and national harm reduction education, interventions, and community organizing. Visit [www.harmreduction.org](http://www.harmreduction.org).

**12steps.org** is a web site that has no official affiliation with Alcoholics Anonymous or any other 12-step group. It is a source for information and tools concerning 12-step programs. 12-step programs have been widely used in recovery programs for addictive or dysfunctional behaviors. Visit [www.12steps.org](http://www.12steps.org).

**Remember the Red Ribbon?**

**Put it back on**

**TAKE ACTION  
AIDS IS NOT OVER!**



**Be Positively Aware!**



Test Positive Aware Network and *Positively Aware Magazine* bring this public awareness message to you. For more information, visit [www.tpan.com](http://www.tpan.com).

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