

REAL HEALTH FOCUS

HIV 101 A guide for black men and women living with HIV

“Other than the stigma, HIV is no different from any other health issue.”



Here's to Your Overall Health

Staying fit and healthy and living well with HIV are closely related. **KELLE TERRELL** reviews the basics.

Many people with HIV already have a lot to deal with in terms of their health—finding and sticking to an antiretroviral (ARV) regimen that suppresses the virus and dealing with the side effects of the treatment and the disease itself. As a result, it's sometimes difficult to remember to focus on other diseases that also acutely affect our community, such as diabetes, cardiovascular disease, stroke, kidney disease, obesity and mental illness, to name a few.

Today, people are surviving with HIV. But with longevity comes the possibility of also experiencing other health problems, especially those related to aging. "Because many people with HIV are doing so well because of HIV drugs, they are living longer and becoming older adults," states Kimberly Y. Smith, MD, an HIV specialist at Rush University Medical Center in Chicago. "And as you get older, [other] health issues become more prevalent. You don't escape them because you have HIV."

If family history, a sedentary lifestyle, unhealthy diet, the use of antiretrovirals or many years of living with HIV have given you a greater chance of developing these diseases, don't worry. There are practical ways to juggle both HIV and other health concerns. There are also places to go and people to lean on in order to receive emotional and spiritual guidance—no one has to go through this alone.

But real talk: In order to live long and healthy, it's going to take the combined efforts of you and your health care providers. "The patient needs to be the controller of his or her own fate, be aware of potential problems and find a doctor or a team," says Dr. Smith.

This *Real Health Focus* is aimed at addressing your whole health: HIV and all.



Queen Bee

Our cover girl, Leatrice Simpson, handles her HIV and other ailments—they do not handle her.

Leatrice Simpson

Age: 45

Diagnosed with HIV: 1992

Diagnosed with diabetes and hypertension: 2007

Real Health: When you were diagnosed with HIV, what were your fears?

Leatrice Simpson: I thought I was going to die. And after two years of worrying about dying, a lightbulb went on and I stopped crying. I started to eat right, take my meds and live with it. Other than the stigma, [HIV] is no different from any other health issue.

Were you surprised when you were diagnosed with diabetes and hypertension?

It wasn't totally

unexpected. My grandmother, who passed, had both; my mother developed both in her mid-50s; and I had two aunts who had diabetes. I do what I need to manage the condition: adhere to my medications, check my blood sugar, exercise regularly and see a dietician to help me choose [diabetic-friendly] foods.

How can other African Americans living with HIV feel empowered about their health?

First, realize that this is a chronic disease and there should be no shame attached to it. Also, try establishing good relationships with all of your doctors and don't be afraid to ask questions.

Time to Treat?

Knowing when to start or switch treatment—and which meds to use—is critical to your HIV care.

Taking medicine can halt the damage HIV does to your immune system, ultimately helping you live longer and healthier. But when it comes to treatment, there are many questions: When do you start?

Which meds do you use? Will you ever need to switch?

In terms of deciding if and when to start treatment, there is no one right or wrong answer—it's different for each person. "Some patients think that if they look and feel healthy, they don't have to be on meds, which is not necessarily true," states Smith. Starting meds, she says, depends on a number of things, including the number of CD4 cells (CD4 count) and amount of virus (viral load) in your blood. "If you're tired a lot and have conditions like skin rashes, recurrent yeast infections and chronic diarrhea, regardless of your CD4 count, I am definitely going to suggest starting HIV treatment," says Smith.

Beyond viral load and CD4 counts are other lab tests that can help you make informed treatment decisions. For example, there's a test available to help you and your doc determine if you're at risk for a severe allergic reaction to abacavir—found in Ziagen and Epzicom—and should avoid the drug. Lab tests can also be used to monitor your health while you're on HIV meds with certain side effects, such as those known to increase artery-clogging cholesterol levels or cause damage to organs like the liver or kidneys.

If, once you have started treatment, your viral load does remain undetectable, your CD4 count continues to fall or you find that the side effects are unmanageable, switching to a new regimen might be necessary. And just as there are different med options for those starting ARVs for the first time, there are also options for those needing to switch.

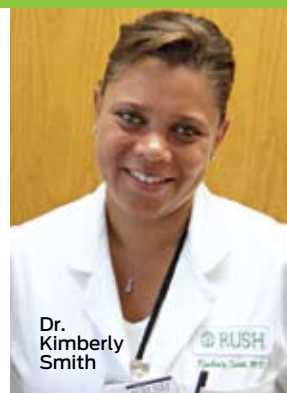
Adherence Assistance

HIV survives by using the cells of your immune system—your CD4 cells—to replicate. The meds stop that replication from happening, so it's crucial to take them every day at the correct time in order to achieve the full benefit. Skipping doses can lead to resistance of not only the regimen you're currently on, but also the combos you might need to take in the future, explains Smith. "This is not just about your health now, but your health down the line."

Suggestions to stay on top of your meds:

Buy a pillbox:

Evidence shows that people who use pillboxes are more likely to take their meds on time and every day. Not only can they help you stay on schedule, but



prying eyes won't necessarily recognize the pills as meds for HIV—anonymity is very important to many of us.

Make it part of your daily routine:

"If you take all of your pills when you go to bed, have the bottles on the nightstand, or if you are taking them in the morning, have them by your toothpaste in the bathroom," says M. Keith Rawlings, MD, of Dallas. "If you find that after a few months these cues are not working, switch them up."

That Ain't True! *Real Health* busts some dangerous myths about HIV:

MYTH 1: THE MEDS KILL YOU, NOT THE VIRUS:

While many believe that AZT, also known as zidovudine (Retrovir), killed people in the early days of the epidemic, it's not true. There were some legitimate questions about the way HIV medications were used in the early years of the epidemic—but we now know how to minimize side effects and maximize effectiveness. Tons of research show that not only can HIV

treatment prolong one's life, it can also enhance quality of life.

MYTH 2: THE ONLY LIFESTYLE CHANGE I NEED IS TO ADHERE TO HIV MEDS:

Remember, meds can extend your life, but focusing on your whole health is key to living well. The healthier you are in general, the better able your body will be to fight HIV and the side effects of its treatment. "I encourage my patients to eat better and to exercise regularly to

reduce the risk of diabetes and other diseases," Smith says.

MYTH 3: THERE'S A CURE FOR HIV, THEY JUST DON'T WANT US TO HAVE IT:

Thanks to the 1932–72 Tuskegee study, during which government doctors allowed syphilis to go untreated in black men to learn about its progression, many of us have a distrust of the medical community. Fact is, there is currently no cure for HIV—but HIV is treatable.

ARV 101

Knowing your antiretroviral (ARV) med options, and the differences between them, will help you have a productive conversation about treatment with your health care provider. The following is a breakdown of the five different classes of HIV drugs—each one prevents HIV from replicating at a different stage in its life cycle:

- Nucleoside/nucleotide reverse transcriptase inhibitors (NRTIs)
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs)
- Integrase inhibitors
- Protease inhibitors (PIs)
- Entry inhibitors (EIs)

HIV meds are taken in combination because one drug is not enough. If you were only to take one or even two HIV meds, HIV could quickly outsmart the meds and your virus could develop resistance to the drugs, which would mean you'd be taking them in vain and not controlling HIV. It takes a team of meds from different classes to control HIV. Standard treatment (often called HAART, or highly active antiretroviral therapy) combines at least three meds. For first-time treatment takers, this often involves two nukes, plus either an NNRTI or a PI. Drugs in the

other classes usually come into play when HIV has become resistant to standard options.

The following are some questions to ask your health care provider when choosing a regimen:

Potency: Is the combo powerful enough to fight my virus and keep my viral load undetectable?

Safety: What kind of short- and long-term side effects will the meds have on my overall health?

Convenience: How many pills, taken how many times a day?

Works well with others: Do they interact with other meds I'm taking?

Rx Tip: Be sure to mention all over-the-counter, prescription and recreational drugs you're taking to your doctor so he or she can warn you about any potentially dangerous drug interactions.

"If you can, make sure that your doctor is calling in [all] your prescriptions to the same pharmacy," advises Dr. Rawlings, the medical director of the Peabody Health Center in Dallas and president of Integrated Minority AIDS Network, Inc. "That way [your pharmacist] has all of your med information and can watch for drug interactions."

Don't Forget Your Annual Checkup

Other key health issues to screen for:

Cardiovascular disease: Heart disease—heart attack, strokes and hypertension—is the No. 1 killer of African Americans every year. Some medications used to treat HIV can raise cholesterol and triglycerides; elevated levels of these substances can cause heart disease. Then again, untreated HIV infection has also been linked to a higher risk for a heart attack. Other issues, such as poor diet, smoking or not getting enough exercise, are risks as well.

Diabetes: High glucose (sugar) levels can lead to serious health problems. Of all African Americans ages 20 years and over, 2.7 million, or 11.4 percent, have diabetes. Also, one study found that HIV-positive men are four to five times more likely to be diagnosed with diabetes than HIV-negative men.

Kidney problems: Cardiovascular disease, diabetes and certain meds can put a strain on your kidneys. Not to mention HIVAN (HIV-associated nephropathy)—a serious type of kidney disease caused by HIV—which is a huge issue for black men living with the virus, notably those who aren't on ARV treatment.

Hepatitis: Hepatitis C, common among positive people, is a major cause of liver-related death. Hep A and B can also cause serious liver complications as well. Have your doctor check for these infections. If you test negative, consider getting the hep A and B vaccines.

STDs: Having HIV does not make you exempt from contracting other STDs, such as herpes, chlamydia, syphilis, HPV and gonorrhea, to name a few. Sexually active women and men should be tested at least once a year for all STDs.

Mammograms: While breast cancer is no more common among HIV-positive women, there is evidence that it can be more aggressive in black women. Don't forget to conduct monthly breast exams at home, and if you are over the age of 40 or have a history of breast cancer in your family, schedule a mammogram every year.



Use the same pharmacy to guard against dangerous drug interactions, says M. Keith Rawlings, MD.

Accessing Care

In order to maintain the health of your whole body, it's important that you and your health care team look beyond your viral load and CD4 cell count. You may be at risk for health problems that come with aging or you may be thinking about starting a family—all require expert medical advice and care. “You can either find one doctor who is equipped to deal with HIV and everything else, or you have to make sure that your primary care doctor can link you to specialists,” states Rawlings.

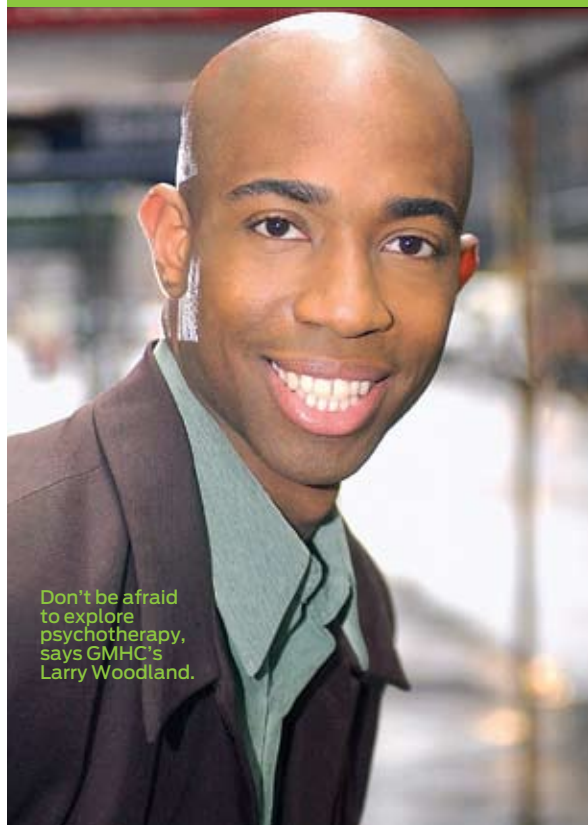
It's also important to keep in mind that health care providers aren't always equipped to answer every question about HIV or to link you to other services you need. This is where AIDS service organizations (ASOs) come in. ASOs may not only be able to link you to care, but can also provide the following: support groups and one-on-one counseling, financial and legal advice, help navigating Medicaid, Medicare and AIDS Drug Assistance Programs (ADAP) or simply provide a place to meet up with other friendly faces or maybe to use the Internet to do research about HIV.

To locate an ASO and other health services in your area, visit *Real Health's* online service directory at directory.realhealthmag.com.

GETTING PROACTIVE

As we said before, it's partly your doctor's responsibility to be on top of your health, but you have to do your part too. Here are some tips to help you become more empowered when visiting your doctor.

- Be honest about your personal and family medical histories, your sexual activity, any drugs you may use, and all other medications you are taking. Keeping information from your health care providers makes it harder for them to optimize your health.
- Read! Doing some homework can make for good conversation, so rip out articles from *Real Health* and *POZ*, show them to your health care provider, and have your questions ready for your appointment.
- If your needs are not being met, find a new doctor. “Doctors don't have a lot of time, but that's not an excuse to overlook time for pressing issues,” Smith states. Remember, this is your health; you deserve to be treated with respect. Adequate health care is not a privilege; it is a right.



Don't be afraid to explore psychotherapy, says GMHC's Larry Woodland.

Mind, Body and Spirit

Nobody is immune from the mental and emotional stresses of living with HIV. Unfortunately, bringing up issues like depression in our community can sometimes prompt responses like, “That only happens to white folks,” or “All you need to do is pray.” The reality is one in five of us suffers from a mental disorder, such as depression and bipolar disease—the same as white people. But one alarming difference is that we are less likely to receive treatment. You are not less of a person if you seek outside help.

Larry Woodland, the coordinator of mental health at New York City's Gay Men's Health Crisis (GMHC), offers these tidbits:

- Educate yourself: Before you pass on mental services, learn what psychotherapy is and what it isn't.
- Seek services in places where you or your loved one feels comfortable, like your local ASO or neighborhood community center. If they don't offer these services, they might be able to refer you to someone who does.
- Therapy is about improving one's life: It can provide feelings of control, give a better sense of self and leave you feeling empowered.

The Importance of Support

Another crucial step in maximizing your whole health is mobilizing your extended support system—family, friends, church family, you name it. If the idea of opening up to someone makes you anxious or apprehensive, realize that you don't have to go through this alone.

DISCLOSURE 101

If you are living with HIV, telling people you're positive and letting them into your life may be physically and emotionally beneficial, but it's not an easy thing to do. Some people still have misperceptions about how HIV is spread and what being infected with the virus really means. Stigma and fear of rejection are reasons why some people prefer to remain quiet about their status. But if you want to disclose, how do you go about it?

"I spent so much energy hiding my status that it was taking a toll on me," admits Nathan Townsend, who was diagnosed in 1984. "But after 22 years, I wanted to be open and I finally accepted myself. And now, I am liberated."

Townsend, an HIV/AIDS awareness educator in Philadelphia, who also works closely with HIV-positive clients, offers these suggestions on disclosing:

- Waiting until you have come to terms with your diagnosis might make it easier to disclose. Consider going through a support route with an ASO or doctor, which may put you in a better position to be honest with others.
- Before you educate anyone about HIV, educate yourself. Townsend says he comes across many positive people who don't know the basics, like how the virus is and is not transmitted.
- Sometimes we unnecessarily project our fears onto other people. Don't always assume that people are not going to accept you.



Lean on Me

Leslie Williams

Age: 50

Diagnosed with HIV in 1993

Diagnosed with hep C in 1989

Recovering heroin addict

Real Health: What did you know about HIV when you were diagnosed?

Leslie Williams: I am no stranger to HIV. My little brother died of AIDS; my father died of AIDS; and my wife, Andrea, is HIV positive as well. When my father was dying, I told my mother that HIV is going to stop with me; my daughters are not going to become infected. I quit using drugs and became serious about taking care of my health. Now my HIV and hep C are under control, and I have been clean since 1994. Determination played a part in that, but so did having support at home and in my community.

Where do you go for support?

My wife, Andrea, and I keep each other alive. She is my backbone—she stays on me to take my meds and she educates me about the virus. I also go to two support groups a week—one for HIV-positive men and one open to anyone. We talk about everything, from meds to what to do if you have sores in your mouth.

Any advice for people who are apprehensive about support groups?

I know a lot of brothers who don't want to talk about what is going on with them, but I tell them to take advantage of what's out there, because I remember a time when there was a lot less [help].



Rev. Doris Green

Church Healing

The black church is the backbone of the African-American community, but it has also, until recently, reinforced HIV stigma and homophobia. Over the years, AIDS ministries—faith-based HIV educational initiatives—have been popping up throughout the country to address the growing epidemic in black America and to provide spiritual support for those infected and affected by the disease.

"This is not about ideologies, or about what is wrong and what is right," says the Rev. Doris Green, the AIDS Foundation of Chicago's (AFC) director of correctional health and community affairs, who is also responsible for developing AFC's *The HIV/AIDS Toolkit for Black Churches*. "It is about spreading knowledge and helping those in need."

Find an AIDS ministry in your area at balmingilead.org or call 888.225.6243.

Want to start an AIDS ministry at your church but don't know how to start?

Download a copy of The HIV/AIDS Toolkit for Black Churches at aidschicago.org.