REALHEALTH™

Should I Take These Pills?

Myths about HIV and treatment abound. How do people—especially those thinking about starting medication—sort fact from fiction? Kendra Lee reports.

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When Jeffrey Green found out he had HIV two years ago, he was dead set against taking the HIV-drug "cocktail." Except for being a little run-down and nursing a constant cold, he felt fine at the time and had "heard around" about the meds' side effects (although not from anyone who was actually on them). "I thought it would make me so sick I'd have to quit my job and everyone would know I was positive," says the 41-year-old Laurel, Md. resident.

Fortunately for Green (not his real name), his doctor took the time to explain that most of the side effects subside during the first month or so of treatment. So Green started taking medications that smacked down the amount of virus in his blood without any side effects at all. "I can't tell you how relieved I am that I'm not sick!" he says.

The best-case scenario

Green took a leap of faith that many African Americans don't get the chance to make. In an ideal world, we would be diagnosed early, have access to care we trust and get the information we need about how treatment works.

But one in five black people doesn't have health insurance, and when we do have access to care, statistics show it's sub-par. Last year, a U.S. study confirmed that white doctors routinely postpone treatment for their black HIV positive patients compared with their white patients. With data like that, not to mention notorious incidents of medical racism like Tuskegee, it's no surprise that black mistrust of U.S. health care runs deep.

But so do discrimination and misinformation in our community, especially about HIV and treatment (ever hear the one about how the drugs actually give you AIDS?). A 2005 survey by the RAND Corporation and Oregon State University found that 27 percent of African Americans believe that HIV was produced in a government laboratory. When Kenyan biologist, activist and Nobel Prize winner Wangari Maathai proclaimed that "AIDS [is] not a curse from God to Africans or the black people.... It is a tool to control them designed by some evil-minded scientists," she was voicing the suspicions of many black Americans, too.

Whatever you believe, this disengagement and mistrust is coming back to haunt us. At a time when new drugs have caused AIDS death rates in the U.S. to plummet, African Americans with HIV continue to get diagnosed late, when their immune systems are weakened, and to die at a faster rate than other people with HIV.

Starting right

The truth is that the drugs do have side effects. But most are short-term, while the long-term ones can be monitored and, for the most part, managed. “If they have diarrhea, there are meds that can help,” says Lloyd Bailey, MD, an African-American physician in New York City who specializes in HIV. “Nausea may be better managed if they take certain medications with food.”

In addition, side effects can vary from person to person. Without drugs, a person with HIV can look and feel fine for a decade or longer. But under the surface, the virus is wearing down the immune system, making the body susceptible to infections. The later you wait to help your immune system, the harder it becomes to control the disease.

The only thing worse than going on meds late, however, may be starting them before you’re ready. HIV drugs are trickier than most medications because if you don’t take them exactly as directed (i.e., if you’re not “adherent”), the virus can multiply, mutate and become resistant to certain drugs. The great risk is running out of treatment options. Bailey tells his patients that taking HIV meds is a lifelong commitment, and if they’re not ready for the once- or twice-daily obligation, they should wait—as long as they’re not too sick—and work on getting ready.

For instance, it pays to tackle substance-abuse issues up-front. “It depends upon an individual’s coping skills,” says Bailey, “and whether they involve drugs and alcohol—because [that] will make the situation more problematic.”

Dr. Bailey recalls a particularly strong-minded young man who refused to go on meds even though his T-cell count—a measure of how healthy one’s immune system is—was getting low. “I took a backseat to his making the treatment decision he felt comfortable with,” explains Bailey, who knew that pressuring this patient might only make him rebel—and possibly miss doses with his virus eventually becoming resistant to treatment.

Bailey’s sensitivity is one approach to rebellious patients. Just ask Marcya Owens about the other: doctor neglect. For nine years now, her efforts to stay on HIV meds have been tripped up by depression and side effects ranging from rashes and headaches to a mild heart attack. But her doctor won’t hear her pleas for an easier combo or a treatment break (some patients doing well on meds can go off for a while with a doctor’s supervision).

“If a person comes to you and says, ‘I don’t wanna be on these meds, I’m not [taking them],’” argues Owens, an East St. Louis, Ill. mom, “that should be a strong hint” that something’s wrong. Owens is thinking about switching docs.

What can you handle?

Dr. Bailey’s main goal is to get patients (many of whom have had bad experiences with medical experts) to see that he understands their issues and can be trusted. “I make it quite clear that there are costs,” says Bailey. “There is going to be some effect on your life. It’s going to require active management.”

And there has to be a dialogue. “Patients have to advise me about their side effects and how much they can tolerate,” he says. With more than 20 medications on the market, patients have many options, especially during their first years of treatment, before resistance can develop.

Victoria Cargill, MD, at the Office of AIDS Research at the National Institutes of Health, says patients need to communicate as specifically as possible. “If someone says I can take bad dreams, but I can’t take diarrhea, that gives me a starting point, and I can think about a different combination of drugs,” she says. “If you’re truly feeling fine, I don’t want to make you feel worse—so you have to talk to me.”

Beyond the doctor’s office

There will always be bad doctors. Edith Lang used to see a white doctor in Dallas who didn’t even bother to examine her when she reported pain in her legs and feet. The physician just assumed that the 45-year-old had neuropathy from her HIV meds and put her on drugs for the condition. Then when she switched docs, the new guy (Keith Rawlings, MD, a black physician who specializes in treating blacks with HIV) proved that Lang didn’t have neuropathy at all.

Sometimes, the best thing a person can do is look for another doctor. Barring that, experts say, he or she should get on a regular schedule of blood counts and checkups and be as open as possible with someone (if not a doctor, then a nurse practitioner or social worker) about everything from sex and diet to alcohol and cigarettes.

For plenty of HIV positive people on meds, support, information and care can also be found way beyond the doctor’s office—in adherence support groups, for instance, or the distraction of a job or family. Frank Hawkins, director of education and outreach at AIDS Delaware in Wilmington, Del., says he encourages patients with nagging side effects to do some kind of volunteer work. “That gets them thinking about somebody else, which helps them put their side effects in perspective.”

Still standing

There is perhaps nothing to compare to riding side effects and adherence challenges all the way to the other side—where one feels better, with lab tests showing a strong immune system again.

Owens, with her list of side effects, is not there yet. But she knows HIV meds have saved her life and has no interest in keeping that to herself when mistrust and myths remain so widespread. “Oftentimes,” she says, “I won’t even share my side effects with someone because I worry it’ll scare them away from treatment.”

The Doctor Is In

What **David Malebranche, MD** (above), Atlanta-based HIV specialist, wants you to know about

HIV meds:

1. **They’re a lot easier to take than they used to be.** “You can take all your pills once a day now, and there’s one that will combine three meds into one pill that you can take once a day” (see page 11).

2. **Most have side effects.** “But it very much depends on the individual. People react to different medicines differently.” And you and your doc can manage them.

3. **They can greatly improve your quality of life.** HIV meds have helped millions live longer, healthier lives.

4. **They’re no cure.** “Even with all the advancements we’ve made, I had a patient who died the other day.”

5. **They’re no substitute for healthy living.** Get enough sleep, eat right, try to avoid stress and excessive alcohol or drug use, get exercise and address your mental health. “If you’re taking your meds, but ignoring the other stuff, you can still have a poor outcome.”
