

POZ FOCUS

QUALITY OF LIFE The Second of a Two-Part Series

Doctor Love

Work with a pro to:

- ✓ Vanquish fatigue
- ✓ Conquer depression
- ✓ Manage body-fat changes
- ✓ Get your life back

"I want to know:
Is everything OK at home?
Are you stressed? If you
don't ask, you don't know
your patient."

—David Malebranche, MD

Doctor Love.

Yeah, we said it. For the three patients featured in this *POZ Focus*, love isn't too strong a word to describe their relationships with their doctors. Listening without judgment and proposing solutions, doctors partnered with them not only to deal with HIV, depression, fatigue and lipodystrophy, but to achieve the foundation of wellness they needed to achieve their dreams. This *POZ Focus*—the second in a two-part series about feeling good and communicating with your doctor—is about getting the most out of this all-important partnership.



Morris and Malebranche beat fatigue (p. 3).

Get the Best Care

Four docs spill the goods on how you can get the most out of working with them

DO see the right doctor

The first rule of a good doctor-patient relationship: “See someone you feel comfortable with, whom you can talk to about anything,” says Theresa Mack, MD, of St. Luke’s–Roosevelt Hospital in New York City. Look for a doctor who stays up-to-date and who is willing to find answers. See “Looking for Doctor Right?,” page 2.

DON'T twist the truth

For many doctors, this is patient rule No. 1. “Some patients are afraid they may hurt my feelings, or that I wouldn't be proud of them if they weren't taking their meds regularly, or if their meds were making them feel bad,” says Lloyd Bailey, MD, of St. Vincent's Midtown Hospital in New York City. Let your doc know if an abusive partner, a stressful work situation, a drug habit or even a broken fridge is interfering with your ability to care for yourself.

DO maximize your time

“If your doctor can't spend 20 minutes with you, she has too many patients,” Dr. Mack says. Ask reception when the doctor is in less of a rush. “With some doctors, the best time is to be the first patient or the last patient of the day,” says Mack. Consider a clinic which is required to give a certain amount of time to each patient. “We have Ryan White funding,

so our sessions have a 30-minute minimum,” says Ruth Greenblatt, MD, of the University of California–San Francisco Medical Center.

DON'T wait forever for appointments

“If it's just a routine appointment, you should be able to get something within 24 to 48 hours,” says Dr. Mack. If it's an emergency or if something is really bothering you, do NOT wait until your doctor is back from vacation. “Ask for the doctor who's covering for your doctor,” Mack says. “Every practice has walk-ins for this reason.”



¿Se habla español?

Busca información sobre el VIH, el tratamiento y los efectos secundarios en www.aidsmeds.com.

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“Be 100% honest. Tell me everything.”

David Malebranche, MD
Emory University
Medical Center
Atlanta

**meet
our
docs**

43%
the improvement in
survival rates among
patients with HIV-
experienced doctors

Source: University of Washington—Seattle

DO prepare and take the lead

“I recommend taking notes, writing down concerns and addressing them in the exam room,” says Dr. Bailey. Past providers may make your medical history available to your current provider, but it’s a good idea to keep all your medical records in a folder at home. Above all, take the lead. “Patients should make the interaction with their health care provider their own.”

DON'T focus on the Joneses

“I feel like people come in with these preconceived notions—‘I want to be on this med because all my friends are on it,’” says David Malebranche, MD, of Emory University Medical Center in Atlanta. “They may not be able to be on it. Treatment is a very individual thing.”

DO feel entitled

Many patients worry that being on Medicaid, Medicare or ADAP will bring them second-class care. Regardless of your insurance status, “you absolutely should expect good communication and a good doctor-patient relationship,” says Dr. Mack. And while the medical profession does have a history of racism, “you can’t expect every non-black provider to be racist,” says Dr. Malebranche. Dr. Mack agrees. “People say, ‘He talked down to me, so I’m not gonna take my meds, I’m not gonna go to my appointment.’” But who gets hurt in that equation? The patient. “Be vocal about how you’re treated,” Dr. Malebranche says. “But don’t let racism keep you from making healthy decisions.”



“Ask your doctor if she likes to communicate via e-mail.”
Theresa Mack, MD
St. Luke’s—Roosevelt
Hospital
New York City



“Make a list of concerns so you don’t forget to discuss them.”
Lloyd Bailey, MD
St. Vincent’s Midtown
Hospital
New York City



“General practitioners and gynecologists can also answer HIV-related questions.”
Ruth Greenblatt, MD
University of California—
San Francisco
Medical Center

63%

of U.S. general practitioners in a 2005 study consider themselves knowledgeable about HIV care.

LOOKING FOR DOCTOR RIGHT?

The best referrals often come from other folks with HIV, or from care providers you like. You can also:

ASK THE ACADEMY

The American Academy of HIV Medicine provides an online list of physicians specializing in HIV (www.aahivm.org; 202.659.0699). Or try the HIV Medical Association (e-mail hivma@idsociety.org or call 703.299.1215).

.org or call 703.299.1215).

ASK AN EMPATHETIC SOURCE

If you’re African American and would like a doctor who is too, visit www.blackdoctor.org or call 312.222.1205.

Most are listed as general practitioners, but many have experience with HIV.

ASK AN AIDS SERVICE ORG

Find one near you in the ASO directory at www.poz.com.



"I feel like I've gotten my life back."
 —Khalid Morris, doctoral student, mind-body health, Atlanta

i fixed fatigue

How Khalid Morris found his groove again

two steps forward, one step back

In 2002, I started my current HIV treatment regimen—and went from a viral load in the hundreds of thousands and a CD4 count of 13 to undetectable with a CD4 count of around 500. But then I had to fight through the side effects. The nausea went away, but a

feeling of fatigue persisted. I literally didn't have the energy to go to the bathroom.

the good doctor Prior to meeting my current doctor, David Malebranche, doctors would just hand me a prescription. Dr. M actually *listened* to me, so I felt like I could listen to him too. First he gave me the good side, telling me these drugs could bring my viral load down. He asked me questions about whether I worked or was in school. He suggested taking the meds at bedtime so I could sleep through the side effects, and I experienced minimal dizziness during the day.

the fatigue fix Dr. M said we could try other treatment options. But other meds still had the possibility of gastrointestinal side effects, which I hated, so I decided to stick with the regimen. We discussed different ideas for the fatigue, like exercise and medication; yoga was the route I chose. I started on my own with a beginner's book. After my first session, I fell asleep! Then I woke up feeling good. I go to free classes twice a week, walk through the park a lot and sometimes jog. Exercise gives me energy and strength.

STARTING TREATMENT

When it's time and what to watch for

the guidelines

Without doubt, CD4 counts are the usual signposts for starting HIV treatment. Meds are suggested for those with counts below 350 and strongly recommended under for those 200. Physical illness is also a reason to start, according to treatment guidelines.

getting adjusted

HIV meds can cause a person feeling bad to temporarily feel even worse. Headaches, diarrhea, nausea and vomiting are common, especially during the first weeks. "Don't stop treatment," warns David Malebranche, MD, "without communicating with your provider." Many of these problems are benign. But some may be signs of something more serious (and rare), including a buildup of acid in the blood (lactic acidosis), a severe allergic reaction, or liver problems, in which case an immediate hospital visit is called for.

NO WAYS TIRED

Feeling wiped out by fatigue? Here's what you can do

why it's important to address it

Exhaustion, sleepiness or lack of energy affect over half of folks living with HIV. Not only does it screw up your quality of life, it can also mess with your ability to take meds on time.

what causes it

Insufficient rest and exercise or inappropriate diet can break your flow. Other causes include anxiety, depression, substance use (including alcohol, tobacco and recreational drugs) and low testosterone levels in both men and women. Another culprit: anemia, in which your red blood cells don't function adequately, resulting in less oxygen delivery. Anemia has many

causes; it is sometimes a side effect of AZT (found in Retrovir, Combivir and Trizivir).

what to say to your doc

Be honest about how you feel. Lifestyle factors—like working (or partying) too hard or not getting enough exercise—may be slowing you down. Also, be sure to ask for blood tests to check your testosterone level and red blood cells.

what's next?

Once you know the source, you and doc can talk strategy. Lifestyle options include eating healthier, treating depression and cutting down on drinking, smoking or drugging. If HIV meds are the cause of anemia, switching regimens may be an option, or adding an anemia drug like Procrit. Treating fatigue directly with Provigil (modafinil) has shown promise.

high on life

Daphne Cooper ditches depression by speaking out—and seeking divine inspiration

a woman's blues I was a victim of incest and physical and mental abuse from birth until 18. That drove me to the streets. I worked in dance halls and went on every kind of drug. It took me to a suicidal place. I found myself at a recovery center—somebody had put me on a bus and said, “You’re killing yourself; you need some help.” My self-esteem was so low. Now I counsel women who are HIV positive. I talk about how I got delivered from a life of prostitution, and I’m truthful with my status.

behind every good woman My doctor, Robert Rocco in Hoboken, New Jersey, is the greatest doctor in the world. He listened. I gave him all my junk. He wasn’t judgmental and never rushed me out of the office. Then he gave me some positive affirmations. When I first walked out of his office, I knew I finally had someone I could work with. We worked until I became undetectable. (And

he’s gorgeous. Hey, I love making appointments.)

decking depression Dr. Rocco started me on Paxil in 2003. Paxil does well for me, but I think it has caused me to put on some weight. But staying active, talking about HIV and writing about it help me. Acupuncture, massage and a support system are great too.

inspiration is my antidepressant Now I say, “Hi, I’m Daphne. I’m positive,” and I tell people about my ministry, Apple of His Eye Outreach. I give gift baskets and dress women free of charge. I’ve been on the radio. I write articles. And I pray and meditate. I’m not religious, I’m spiritual. There’s a man upstairs keeping me alive. He works with the doctors and the meds, but I’ve got to work too. Now I tell myself that I’m beautiful and I’m powerful. I’ve soared to a level I never thought I would reach.



“I’ve soared to a level I never thought I would reach.”
—Daphne Cooper,
HIV educator,
Jersey City

THE ROAD TO HAPPY

What to do about depression

how do I know I’m depressed?

Everyone gets “the blues,” temporary feelings of unhappiness and frustration. Much more serious is depression—long-lasting symptoms of intense sadness, low self-esteem, loss of pleasure and, in some cases, difficulty functioning. Left unchecked, depression may result in neglect of personal and work-related responsibilities, poor HIV-treatment adherence and increased and excessive use of alcohol or other drugs.

what causes it?

Depression is a psychological illness with biological causes. It can be the result of an imbalance of neurotransmitters, chemicals that carry signals in your brain and nerves. It can also be tied to low levels of hormones, like testosterone, as well as anemia (decreased red blood cell counts).

how to bring it up with doc

If you think you may be depressed, begin by talking with your primary-care or HIV doctor, who may be able to figure out the underlying cause. For example, if anemia or low testosterone is found in your lab tests, steps can be taken immediately to remedy the problem. Your doctor may also refer you to a specialist, such as a psychiatrist, psychologist or psychotherapist, who can diagnose you and start you on a course of weekly “talk therapy” or antidepressants.

treating depression

Strategies for dealing with depression will depend on the cause. For example, anemia may be reversed by switching HIV meds; testosterone gels or shots may help boost low levels of the hormone. There are also antidepressant medications, generally considered to be the quickest way to relieve severe depression—but your doctor, nurse-practitioner and pharmacist should be on the lookout for interactions with HIV meds. Psychotherapy, or talk therapy, is also helpful. Combining meds and talk therapy may work best.

QUICK TIPS

- ✓ **Take a depression screening test** online at www.med.nyu.edu/psych/screens/depres.html and tell doc.
- ✓ **Check for interactions** between your HIV meds, antidepressants and anything else you might be taking at www.aidsmeds.com (click on Cool Tools).
- ✓ **Docs: Ask about factors which can disrupt treatment**, like depression, drug use, domestic violence and overwork or unemployment.



“Did the switch improve my lipo? It hasn’t gotten worse.”
 —Derek Thaczuk, writer, treatment advocate, Courtice, Ontario

face time

To stop the fat loss in his cheeks, Derek Thaczuk switched HIV meds

who’s that man? I was visiting an aunt one day when, just out of the blue, she asked me what was wrong with my face. (That’s my family for you, straight to the point!) I ducked the question somehow, but that changed something for me. Before then, I’d done a good job of pretending the lipo didn’t bother me. But there hasn’t been a day since then that it hasn’t been on my mind—and I really don’t like to see my own pictures.

your face or your life It took years to become undetectable. (I remember yelling and jumping around when the clinic nurse called with the good news.) I was diagnosed positive in 1992 and started antiretrovirals

in ’95—the days of monotherapy. I built up a lot of drug resistance; at one point, I really didn’t think there were any options left. But in 1999, my docs put together the five-drug combo that did the trick.

busting a move My doctors and I realized which drug was causing my lipo and switched to something else. That decision took a bit of guts: I didn’t want to screw up my hard-won success because of something that felt like vanity. But I have great docs, and I know my way around meds pretty well. (I work as a treatment educator, after all!) We discussed the switch thoroughly and were confident it wouldn’t jeopardize my treatment—and it hasn’t. Did the switch improve my

THE L-WORD

What you need to know about unusual fat loss or gain, aka “lipodystrophy”

what is “lipo”?

“Lipo” refers to fat; “dystrophy” means unusual change. In plain English, lipodystrophy describes the gamut of body-fat changes seen in some people living with HIV. Symptoms include a buildup of fat (lipohypertrophy) around the gut, the breasts or on the back of the neck and shoulders. There can also be a loss of fat (lipoatrophy) in the legs, arms, butt or face. Increased fats in the blood, notably cholesterol and triglycerides, may also be seen and can put cardiovascular health in jeopardy.

what causes it?

Protease inhibitors can weaken the activity of certain enzymes in the body that mop up excess fat and keep fat cells working, leading to fat accumulation. Nucleoside analogues, including d4T (Zerit) and to a lesser extent AZT, have been linked to lipoatrophy. People over 40, who are white or who start HIV treatment with CD4 counts below 100 may also be at increased risk.

talking to your doc

Keeping an eye on your blood fat levels and regular chats with your doc are important. Body-fat changes can increase the risk of heart disease, cause discomfort and can have a serious effect on how people feel about themselves.

what you can do

We still don’t completely understand what leads to lipodystrophy. But a healthy diet and cardio exercise may help with fat gain, while strength training may help build muscle in place of lost fat. Talk to your doctor about whether it’s possible to switch to HIV meds less associated with lipo or to add a med that may help correct lipohypertrophy. Liposuction can remove some, but not all, excess fat deposits, while implants of fat or fat substitutes can fill out sunken cheeks. For more on lipo, search www.poz.com.

lipo? I’m not sure. But it hasn’t gotten worse—and I’m sure it would have if I hadn’t switched. My doctor agrees with me.

the next step I’ve worked in HIV for 12 years, so part of me thinks I should wear my thinning cheeks as a badge of survival. But I still catch myself in the mirror, imagining what a facial fill would look like. For the longest time, I’d written that off as financially impossible. But recently I’ve looked into it more closely: It’s not

cheap, but it’s not hopelessly out of reach. (Plus, the clinic has a partial subsidy I may qualify for.) So now I’m saving up. The worse your lipo, the more it costs—so if we hadn’t nipped this in the bud when we did, I’m sure this wouldn’t even be an option.



What did you think of this supplement? Visit www.poz.com/feelgood2



AGING AND HIV

Your golden years bring wisdom—and new challenges

HIV treatment can prolong survival, hopefully without AIDS-related health problems. But everyone, regardless of HIV status, faces the health challenges of aging. In addition, HIV and its meds can cause problems that we're all at higher risk for as we get older.

body shape

HIV treatment has been linked to fat gain, especially around the gut, as well as fat loss, particularly in the face, legs and arms (see "The L-Word," page 5). In fact, fat gain with age doesn't appear to be any more common in people who are HIV positive than in those who are HIV negative. Fat loss in the extremities, however, is more frequent and pronounced among those on HIV meds.

bones

HIV treatment has been linked to osteopenia and osteoporosis—a drop in bone-mineral density. Fosamax (alendronate), combined with calcium and vitamin D, has been shown to be useful in positive folks with osteoporosis and advanced osteopenia.

heart health

The older we get, the more important it becomes to keep blood pressure low and cholesterol, triglyceride and blood-sugar within healthy ranges. High levels of these, which increase our risk for heart attack or stroke, are also possible side effects of HIV treatment and, possibly, HIV itself. While we can't control the march of time or our need for HIV meds, we can control some things which affect our heart risk, including smoking, diet and exercise.

CHECKLIST

It's one thing to know the importance of communicating how you feel to your doctor. But it helps to write down any problems or symptoms you're experiencing. Fill out this checklist of questions and bring it with you to your next doctor's appointment.

1) If you're NOT YET on HIV treatment, have you had any problems with:

- Fevers?
- Diarrhea?
- Weight loss?
- Fatigue?
- Poor concentration?
- Depression?
- Decreased sex drive?
- Other issues? _____

2) If you're currently taking HIV/AIDS medications, have you had any problems with:

- Nausea or vomiting?
- Diarrhea?
- Other stomach concerns?
- Fatigue?
- Weight loss?
- Changes in your body shape?
- Depression?
- Decreased sex drive?
- Other issues? _____

3) Have changes in your health or how you feel affected your ability to:

- Walk or run?
- Do your job?
- Care for loved ones?
- Spend time with friends?
- Practice good hygiene (bathing, showering or brushing your teeth)?
- Perform household chores (housekeeping, cooking, etc.)
- Exercise?
- Have sex?
- Engage in other activities? _____

4) Before you were diagnosed HIV positive, which daily activity did you value the most?

- _____
- Are you still able to do this activity?
- If not, why not? _____