How to Survive and Thrive

January 31, 2014 By Tim Murphy

Today, HIV medications make it easier than ever for most people to live a long and healthy life with HIV. But regardless of whether you're starting treatment for the first time or are a long-term survivor, you also need to take care of your whole health—your heart, liver, kidneys, bones, mind, etc. You need to look at the whole picture: Think of your life and wellness as a feature film starring you.

"Now more than ever, people living with HIV have to remember that HIV isn't the only thing on the plate to attend to anymore, like it was back in the pre-HIV-cocktail days," says Jeannine Bookhardt-Murray, MD, chief medical officer at Harlem United, which cares for hundreds of HIV-positive New Yorkers. "You have to move forward now with the assumption that you're going to live a full life, and that you have to prevent, screen for and treat everything else that can come up, from heart disease to high blood pressure to depression to overall physical fitness. It's all part of taking the 360-degree view of a happy, healthy life."

So where to begin? Your journey to long-term health starts with getting connected to care and treatment. People living with HIV should consider starting treatment before HIV has a chance to do serious damage to their immune systems. In addition to protecting you from AIDS-related problems, early treatment may also lower the risk of several conditions not usually tied to HIV infection—such as heart, liver and kidney disease, as well as a variety of cancers. (See sidebar, "Meds Matter.") Your chances of gaining long-term benefits from antiretroviral (ARV) treatment are excellent, but it requires careful planning with your health-care provider to choose HIV meds that are right for you.

With more than 20 HIV meds now on the market, you and your health care provider must consider many factors when building a regimen, including your individual health history, treatment experience, dosing schedules, possible side effects and interactions with other medications you're taking. Drug resistance tests should also be taken to help determine which drugs are your best options. Once you decide on a treatment regimen, it's essential that you take your ARVs correctly and on time to protect your health. This is called "treatment adherence."

Regular lab tests are essential to your lifelong wellness. They can help you and your health care provider monitor how you're doing and ensure that the HIV meds are working properly. In addition to measuring your CD4 counts and your viral load, it's important that your doctor or health care provider regularly screens you for a variety of things that can sometimes be bigger issues in people with HIV, even if they're on treatment, such as:

- Cardiovascular disease
- Diabetes
- Hepatitis
- Liver and kidney problems
- Bone density
- Non-AIDS-related cancers (including anal, liver, lung and skin)
- Mental health

It's important to have a good relationship with your doctor or health care provider because you need to feel comfortable asking questions and discussing your most personal issues with him or her. If you don't know where to go or whom to ask for advice on finding a doctor with experience treating people with HIV, then try contacting your local AIDS service organization—they usually have a list of recommended doctors in your area. (Search the POZ Health Services Directory at directory.poz.com.) Keep a list of stuff that's bugging you, physical and mental, and take it with you to your next doctor's visit.

"Any doctor who dismisses a concern you have or a desire to be checked for something should be able to give you a respectful, clear reason why," says Antonio Urbina, MD, associate medical director for the Spencer Cox Center, which treats thousands of HIV-positive folks at St. Luke's-Roosevelt Hospital in New York. "If you feel like you're not being heard, do everything in your power to find another doctor, one who'll really listen to you. Your health and wellness is too important to leave up to a doctor who sees you only as the sum total of your CD4 count and your viral load."

Take Mechelle Jones, 53, for instance. This Bronx grandma and church singer, an admissions director at a health agency, was diagnosed with AIDS in 1995 but, thanks to modern meds, has had her HIV under control since then. (She's also gotten clean from drugs.) "I've had my doctor since 1997," she says. "He's been with me through my ups and downs." What have they really had to watch? Her kidneys. In 2004, after a period of chronic sickness and fevers, Mechelle was diagnosed with sarcoidosis; inflamed cells called granulomas had invaded her kidneys. Mechelle and her doctor identified the problem via abnormal readings of creatinine, a waste product created by the body and usually cleared by the kidneys—and something that should be routinely checked during labs.

A course of steroids, which knock out inflammation, cured her. "I haven't had a problem with it since," she says, noting that she would not have flagged the disease if she hadn't been regularly seeing her doctor and having routine screenings. "Now I just try to live healthy and treat my kidneys and my whole body well. I've given up Pepsi!" she boasts. (And that's a good thing; sodas are loaded with sugars that can lead to insulin resistance, diabetes, obesity and more.) "I try to drink a lot of water, minimize my salt intake and eat as much healthy food as possible, like salads,

steamed fish, fruits and vegetables. I try to avoid fried foods. And I try to take a walk every day with my colleagues." (You can improve every aspect of your health, from heart to bones to mood, by taking at least one good walk a day.)

"Make sure you ask your doctor if he or she is testing you regularly for proper function of all your key organs, including heart, liver and kidneys," Urbina says. "HIV meds have come a long way in terms of not having side effects, but certain HIV meds can combine with certain medical histories to take a toll on your organs, so it's super important to be checking organ function regularly via blood and urine tests."

Such tests were key to saving the life of Fernan Royo, 54, a native Argentinian who owns a gay-themed gift store in Manhattan. Diagnosed with HIV in 1985, Royo's a long-term survivor. "I'm blessed to have never had a problem with my HIV," he says. But there was another bogeyman lurking in Royo's family history: aortic aneurysms, in which the aorta, a key part of the heart, enlarges and bursts. "My grandfather died of it," Royo says. Hence, Royo was always vigilant about having his aorta checked; late last year, doctors told him that it had enlarged to 6 centimeters in diameter—a huge red flag.

Royo needed to have surgery to have his aorta replaced—and he had to forego his beloved daily gym routine leading up to it. "That was really tough, as the gym is my ritual," he says. Then came the procedure itself. "It took seven hours. Recovery was excruciating the first week," he recalls. "I don't do well with anesthesia, and I was very bloated, hallucinating." But Royo is a trouper; six weeks later, he was exercising again and, remarkably, 15 weeks later, he did the AIDS Ride from San Francisco to Los Angeles. He attributes his speedy recovery to the fact that, since he gave up drinking, drugs and smoking in 2001, he takes excellent care of his body and mind.

"I work out all the time, eat lots of veggies and salads, and stay very connected to my family and friends," he says. "I take a nap every afternoon around 5 p.m., I read everything I can about new HIV research and therapies, and I stay on top of my health. If I see a spot anywhere on my body, I'm at the doctor's, saying, 'Hey, what's this?'" Royo says that his nearly 30 years with HIV have given him a keen sense of appreciation for life. "I buried several friends and my lover of 10 years," he says. "I saw Dallas Buyers Club recently and felt such a sense of gratitude for my life and my health. HIV has given me that."

But sometimes doing all the right things and having a great attitude, like Royo's, aren't enough to keep us from feeling down, demoralized, hopeless or anxious. "Depression's a real issue in many people with HIV," says Bookhardt-Murray of Harlem United. "Fear and shame around disclosing HIV to dates and loved ones, feeling vulnerable and isolated and worried about the future—it's perfectly understandable that people feel those things from time to time, and it's important to talk to your doctor and your whole support network about them, shame-free. There's a lot you can do to get relief, from medication to talk therapy to lifestyle changes and spiritual solutions."

Mark Leydorf is a 45-year-old New York City writer and editor who had a history of depression before his 1995 HIV diagnosis, but he took a downward turn after that, trying to forget his HIV

status with alcohol and drugs. “It was like I needed a ticket out of myself, but these fixes never worked for long,” he says. “I was lucky enough to wake up and get sober. In recovery they teach us that the way around a problem is through it, and there was a lot I had to go through to really process my feelings without tuning out with drugs.” Luckily, Leydorf was already on antidepressants and in therapy before his HIV diagnosis, which gave his recovery a solid foundation.

But a few years ago, he started feeling listless and hopeless again. “My therapist and I tried a different antidepressant, I tried doing more 12-step meetings—nothing helped,” he says. “Finally, my HIV doc suggested we look at my testosterone. Sure enough, it was getting very low. This is fairly common in men who’ve been HIV positive as long as I have. With testosterone replacement therapy, my energy level picked up, my mood brightened, my libido returned, and I started writing and working out again. So sometimes it is physical.”

It all just goes to show: You can’t just assume that because your HIV is under control you can ignore the rest of your health and wellness. Says Urbina: “As people age with HIV, they’re vulnerable to accelerated, augmented rates of things that happen to us as we age, anyway, from heart disease to bone-density loss to low testosterone. You have to maintain that positive partnership with your care provider and make sure you’re checking in about every three months to screen all the factors affecting your health profile.”

And between those visits? Then it’s all about something called “lifestyle”—how we treat ourselves every day, and taking our HIV meds is just the beginning. And while “lifestyle” may sound easy-breezy, it encompasses habits that can be hard to get used to, even though we’ll soon start feeling the payoff.

Chelsea Wasak is a marketing student in Denver with plans to open her own “half-country, half-rock-n-roll” restaurant. She was born with HIV (her mom got it unknowingly from a boyfriend) but has never had any major HIV-related complications. “I feel very blessed,” says the 22-year-old Wasak, who also has a culinary-school fiancé.

Her main health challenge is her weight. “I weigh about 200 pounds now, and with my age and height, I’m supposed to be about 150 to 175,” she says. And this affects not only her physical health but also her overall sense of self-esteem and wellness. So when she moved from Rhode Island to Denver last summer, she embarked on a new eating game plan as well.

“I pretty much only eat chicken or ground turkey now,” Wasak says. “No beef.” (Research shows that quality lean protein like game or fish is better for us than red meat.) “Add to that a lot of fruits and vegetables. I drink more water and juice now. I used to drink a ton of soda, two to three cans a day.” Plus, with her culinary-school fiancé, Wasak is learning to make healthy eating fun. “I go on the Internet and find healthy recipes that give me flavor. Salsa’s really healthy for you. I’ll add that to ground turkey and veggies. It fills me up, so I don’t eat a snack at night.”

Changing up her lifestyle game has also meant moving more. “I walk three times a week now,”

Wasak says. “Plus, my new apartment has a gym, so I’ll hit the treadmill with an audio book, then pump out some sit-ups.” Her goal weight? “One-sixty,” she says. “I’m gonna get there. God put me here for a purpose, and after all these years, I’m finally finding out what it is.” So can you. Just remember that HIV is only part of your health story. To live your best life, remember to look at the big picture. After all, don’t you deserve a blockbuster?

Mechelle JonesBill Wadman

Starring: Mechelle Jones, 53, health executive, the Bronx, diagnosed with HIV in 1995
The Conflict: Ten years ago, Jones was diagnosed with granulomas in her kidneys.
The Plot Twist: A course of steroids cleared that up. Since then, Jones walks more, eats more steamed veggies and sings in her church choir. She also gets a whole-body checkup every three months.
The Resolve: “Kidney function’s good right now, thank the Lord. I’ll stay on top of it with my doctor.”
Memorable Line: “It isn’t easy to exercise and eat right all the time. Take small steps. You’ll see the change soon enough.”

Fernando RoyoCourtesy of Fernando Royo

Starring: Fernan Royo, 54, storeowner, Manhattan, diagnosed with HIV in 1985
The Conflict: Royo had an enlarged aorta that threatened to kill him.
The Plot Twist: Thanks to regular screenings, Royo and his docs caught it in time. Aorta replacement surgery was tough, but because Royo was already in excellent health, he rebounded quickly.
The Resolve: “I feel so much gratitude for my life. I stay close to family and friends and take my wellness very seriously.”
Memorable Line: “Have a great relationship with your doc, stay informed about HIV research, take life one day at a time, and make the most of today. Oh, and get lots of sleep. Take naps!”

Mark LeydorfCourtesy of Mark Leydorf

Starring: Mark Leydorf, 45, writer and editor, Manhattan, diagnosed with HIV in 1995
The Conflict: After years of living stable and sober with HIV, Leydorf started to feel listless and depressed. An antidepressant change, more therapy and even attending more 12-step meetings didn't help.
The Plot Twist: Leydorf alerted his doc, who suggested low testosterone might be the issue. Bingo! Leydorf went on testosterone replacement therapy, and his energy and mood surged.
The Resolve: "There's no shame in being depressed, just like there's no shame in having HIV. But you have to reach out and ask for help."
Memorable Line: "If you're diagnosed with depression, accept it like you accept your HIV diagnosis. If you need meds for your mood, take them. If you need therapy, really invest your energy in it. Depression feeds into addiction for many of us, and addiction will take us out of the picture a lot faster than HIV."

Chelsea WasakCourtesy of Chelsea Wasak

Starring: Chelsea Wasak, 22, student, Denver, born with HIV (pictured with her cousin, Parker)
The Conflict: “I need to get from 200 pounds to my goal weight of 160.”
The Plot Twist: Replace the soda and bedtime chips with chicken and fish livened up with healthy salsas. Walk three times a week and take that audio book down to the gym in her building.
The Resolve: “I’m already feeling a whole lot better.”
Memorable Line: “Set an achievable goal for yourself every day. They add up fast.”
