

# POZ FOCUS

**LIVING WITH HIV** A guide to your long-term health



# Living With HIV

By Liz Highleyman

**T**he fact that HIV-positive people can live long, healthy lives comes as a surprise to many, including Hector Melia, a 49-year-old native of the Bronx, New York. “I found out that I had HIV in 1991 when I had a really bad infection in my foot,” he said. “My doctors didn’t think I would live for very long, and I didn’t think to question their logic. But I’m still here, almost 20 years later.”

Melia, however, will be the first to admit that his long-term survival hasn’t always been easy. “I’ve been on [HIV] medications for 15 years,” he says. “It was hard, getting used to the pills and the side effects, but I’m really good about taking them.” In fact, he credits his good adherence for his excellent lab results: an undetectable viral load and 410 CD4s at last count.

His healthy numbers keep Melia at a low risk for typical AIDS-related problems, such as opportunistic infections (OIs) and wasting syndrome. But he, like many people living with HIV, must consider other challenges when it comes to long-term living with the virus—and its treatment.



For example, long-term antiretroviral (ARV) treatment requires long-term planning, not only with medical issues, but also with services and support you might need to ensure that nothing gets in the way of your health care. What’s more, people with HIV may be at an increased risk for age-related health problems, such as cardiovascular disease, and need to take steps to prevent and treat them.

This *POZ Focus* explores some tips and tricks to surviving and thriving with HIV. “Every morning, I look in the mirror and tell myself, ‘I can do this,’” Melia says. “I’ve been blessed with many more years than anybody thought was possible”—and he fully expects to enjoy many more.

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*POZ FOCUS* is an educational series on specific topics relevant to HIV. The editorial content is independently produced by Smart + Strong. This *POZ FOCUS* was supported by advertising exclusively from Gilead Sciences, Inc.



# Going the Distance

## The journey to long-term health starts with treatment

Whether you're starting therapy for the first time or are a treatment veteran, your chances of gaining long-term benefits from ARV treatment are excellent. But this requires careful planning, including choosing HIV meds that have been proven to push viral loads to undetectable levels—and to keep them there for as long as possible.

### When to Start

Treatment options for HIV-positive people have never been easier to take—or safer and more effective over the long run—than they are now, especially for those starting their first, or even their second, drug regimen.

In fact, modern-day ARV improvements over older first-line therapies that came about in the mid- to late-1990s have led many experts to recommend starting treatment earlier than was suggested in the past.

We've always known the importance of starting ARVs before the CD4 count falls below 200, when AIDS-related OIs and cancers become a risk. U.S. treatment guidelines now recommend starting treatment when CD4s fall to 350.

However, research conducted during the past few years hints that starting even earlier might be best. Clinical trials testing this theory are now under way.

"Today, there's much less focus on how long can we wait to start HIV treatment, and more on why not start now," says Paul Volberding, MD, co-director of the

Gladstone Institute of Virology and Immunology Center for AIDS Research at the University of California in San Francisco and one of the first doctors in the world to treat people with HIV/AIDS.

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. The longer HIV goes untreated, the newest research indicates, the greater the risk of harm.

### What to Use

With more than 20 meds to choose from, you and your health care provider must consider many factors when building a regimen, including your individual

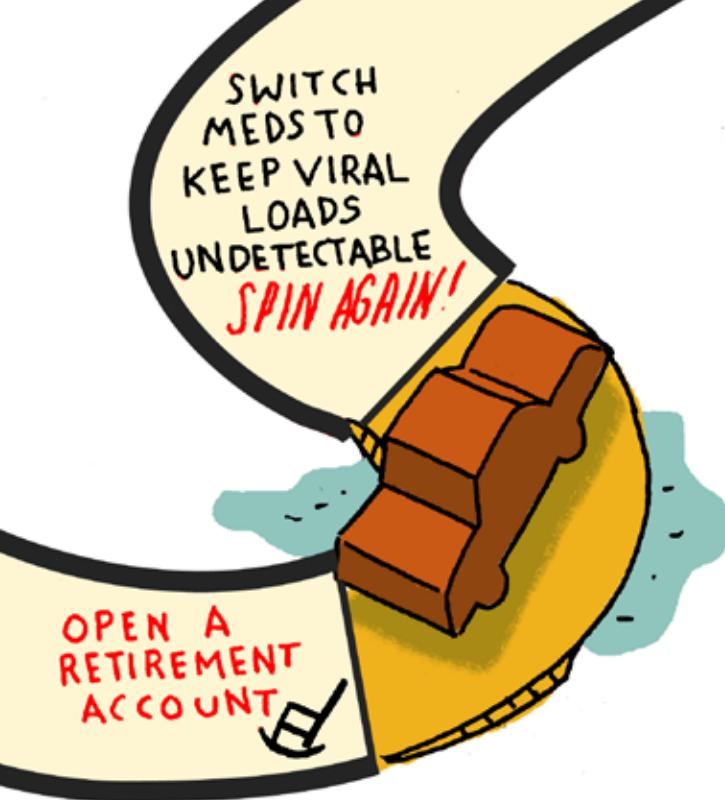
## How Long Can I Live With HIV?

Although there's no easy answer to this common question, study estimates are highly optimistic.

According to a recent study by an international team of researchers, an HIV-positive 20-year-old starting treatment for the first time can expect to live to about age 69—just 11 years short of the average life expectancy for HIV-negative people.

"Having HIV could speed up the aging process and shorten your life span somewhat," says Joel Gallant, MD, associate director of Johns Hopkins AIDS Service in Baltimore. "But I expect most of my patients to be doing great long after I've retired."

Life expectancy for a person starting HIV treatment today is about 13 years longer than it was when combination therapy became the standard-of-care in 1996. This suggests that, as treatments continue to improve, as they have over the past 10 years, expected survival will likely continue to increase.



## Lab Tests for Long-Term Success

Lab tests are essential to lifelong wellness with HIV. Not only can they help you determine when to start treatment and which ARVs to use, but they can also help you and your health care providers figure out how you're doing and ensure that you're not experiencing any harm from your treatment.

**CD4 cell count** measures the number of disease-fighting white blood cells. This gives a snapshot of your immune system health and shows when to begin treatment.

But before starting a new regimen, you should take several tests to help decide which drugs are your best options. These include **drug resistance tests**; the **HIV tropism test**, which determines whether you can use the CCR5 entry inhibitor Selzentry (maraviroc); and the **HLA B\*5701 test**, which figures out whether you're at risk for a life-threatening allergy to abacavir—found in Ziagen, Epzicom and Trizivir—and should therefore avoid that drug.

**Viral load tests** measure HIV genetic material (RNA) in your blood and show whether your current regimen is working properly.

If not, drug resistance tests can show why treatment is failing and spell out which drugs you may want to switch to.

Tests for drug side effects show where you might experience problems. These include **cholesterol tests**, **liver function tests** and **blood cell counts** to detect fatigue-causing anemia.

health history, treatment experience, dosing schedules, expected side effects and possible interactions with other medications you're taking.

Of course, effectiveness is also a major factor. It's important to use a combination of ARVs that's potent as well as durable. This means you'll want to consider meds that can quickly push your viral load to "undetectable" (less than 50 copies/mL using today's viral load tests) and can keep it there. And while you play a big part in this—HIV meds are only effective if taken exactly as prescribed—some meds have been better studied than others in terms of their ability to go the distance.

Whereas many ARVs are studied in clinical trials lasting about a year, some have been evaluated—and compared with other HIV medications—in studies lasting several years. And while a lot can be said for medications that have been available in the "real world" for many years, there's nothing quite like long-term clinical trial data to help determine the likelihood of long-term treatment success.

According to treatment guidelines from the U.S. Department of Health and Human Services (DHHS) for people starting HIV therapy for the first time, Sustiva (efavirenz), a non-nucleoside reverse transcriptase inhibitor (NNRTI), is listed as a "preferred" ARV. One of its first studies, comparing Sustiva plus Combivir (zidovudine and lamivudine) to a protease inhibitor (PI) called Crixivan (indinavir) plus Combivir, followed patients for more than three years (168 weeks). At that time point, 48 percent in the Sustiva group, compared with 29 percent in the Crixivan group, had undetectable viral loads.

Long-term clinical trial data also support Kaletra (lopinavir/ritonavir), a DHHS-preferred PI. One study followed 100 HIV-treatment newbies taking Kaletra plus Zerit (stavudine) and Epivir (lamivudine). After 312 weeks of treatment—almost six years—viral loads were still undetectable in 62 percent of the patients.

Long-term studies have also shown that not all nucleoside/nucleotide reverse transcriptase inhibitors (NRTIs) are equal in their effectiveness or possible side effects. (First-time treatment takers almost always use two NRTIs with an NNRTI or PI.) For example, a study conducted by Gilead Sciences—it was called Study 934—compared its Truvada (tenofovir and emtricitabine) to longtime dual-NRTI champion Combivir—both in combination with Sustiva. After 144 weeks, or nearly three years, 71 percent in the Truvada group maintained undetectable viral loads, compared with 58 percent in the Combivir group. Combivir was also more likely to cause several side effects than Truvada in this study.

Study 934, Dr. Gallant says, is one trial that moved doctors away from a particular group of NRTIs called thymidine

analogues—zidovudine (found in Retrovir, Combivir and Trizivir) and Zerit—for initial HIV treatment. “We learned that while they’re effective, they have definite long-term side effects, including anemia, neuropathy and lipoatrophy [fat loss].”

A study comparing another popular two-in-one NRTI combination—Epzicom (abacavir and lamivudine)—with Truvada, for 96 weeks of treatment, has not yet produced its final follow-up results.

## Are You Experienced?

If you started ARV treatment years ago and have tried many medications, you may have drug-resistant virus, which can chip away at your options. But even if you have lot of treatment experience under your belt, today’s potent meds can usually push viral load below 50 copies—“undetectable”—and keep the CD4 count above the danger zone.

But finding a regimen that can do this may be tricky. For example, if your HIV has become resistant to one drug in a particular class—such as the PIs or NNRTIs—it may limit your ability to use other members of this class.

Some people with HIV that’s resistant to several drugs may not be able to keep their viral load undetectable. But studies show that ARV therapy can still help maintain long-term health by lowering the amount of virus and reducing the damage it can do.

Two recently approved classes of ARVs that attack HIV in new and different ways—integrase inhibitors and CCR5 antagonists—offer new choices for treatment veterans with highly resistant virus.

“It’s critical that new meds be ‘protected’ by using them only in combination with other active drugs,” Gallant emphasizes. “Expert care is always important, but it’s especially important at this stage.”

## Look How Far We’ve Come

Dr. Paul Volberding was on his first day on the job in the summer of 1981 when San Francisco General Hospital saw its first patient with Kaposi’s sarcoma (KS), a rare skin cancer that would become synonymous with AIDS.



“The epidemic absolutely exploded,” he says. “I talk to interns now who were born after the appearance of AIDS. They have no idea how terrible it was, how many sick young people were in hospitals during those years.”

Today, it’s a whole different ball game. “The meds today are amazingly effective, and we’ve stopped using most of the drugs that cause most of the bad side effects,” he says. “At the easiest, it’s one pill a day. At its worst, if a person can help with good adherence, we can still usually suppress the virus even if it’s seriously resistant. HIV is now a chronic disease—which is nothing we even dreamed about early in the epidemic.”

But 25 years on, Volberding sees new challenges. “Early in the epidemic, we did HIV and only HIV. Patients came in sick, stayed sick and died,” he says. “These days, antiretroviral therapy itself is usually straightforward. But now we see patients with a broad range of internal medicine problems. Today, if you’re treating HIV, you must know your diabetes care, hypertension care and all the rest.”

And, he adds, there’s still a lot of work to be done—including expanding the benefits of new therapies to HIV-positive people in the rest of the world. “We’re not giving up on the possibility of totally eliminating the virus from the body,” he says.

(VOLBERDING) COURTESY OF VOLBERDING



## Can I Take a Break From Treatment?

Many people living with HIV hanker for a “drug holiday”—a reprieve in their daily medication ritual—but ample data show that this is usually a bad idea.

One large study found that people who stopped their drugs when CD4 count rose above 350—then restarted treatment when their CD4s fell below 250—had more AIDS-related opportunistic illnesses than people who stayed on continuous treatment. In addition, they also had more serious heart, liver and kidney problems and saw no improvement in side effects or quality of life.

“The arguments for treatment interruption have been pretty much disproven,” says Dr. Volberding. “You interrupt therapy at your peril. I would really try to avoid it.”

Treatment interruption may be the right choice for certain individuals, for example someone who is experiencing severe side effects or is having surgery.

But it's important to never just stop taking HIV meds on your own—this can be a tricky and risky process. If you need to stop, talk to your doctor and make a plan that fits with your long-term health strategy.

# Beating the Odds

## Keeping healthy involves more than meds

As HIV-positive people live longer, they're prone to the effects of aging, which can include bone loss and a rising risk of heart disease, diabetes and cancer. And if you have hepatitis B or C, you also need to worry about your liver.

Experts still don't completely understand how these problems relate to HIV infection itself, drug side effects and the normal aging process, but there's growing evidence that long-term HIV infection can cause problems even if meds help your CD4s stay high.

“Ongoing immune activation [due to HIV] ends up being a lot like inflammation, and with many chronic inflammatory diseases, aging is accelerated,” Volberding explains. “Many people can fully suppress the virus long-term, but we still expect some health consequences.”

Luckily, you can do a lot to lower the odds of chronic health problems, such as undergo healthy lifestyle changes and get regular lab tests.

“We are what we eat,” says Donald Abrams, MD, director of clinical programs at UCSF's Osher Center for Integrative Medicine, who also treated some of the first AIDS patients in the early 1980s. “Don't be a fast food junkie. Eat a plant-based diet with lots of fruits and vegetables and whole grains. Drink green tea instead of cola.”

He also advises exercising at least 30 minutes a day, maintaining a healthy weight, quitting smoking and finding ways to reduce stress “whether it's meditation, massage, nature or spirituality.”



# Staying a Step Ahead

## Successfully navigating the road ahead requires a plan

Like everything in life, living long-term with HIV requires a strategy. This means working with your health care team—including your medical team, your social worker or case manager and others you rely on for care and support. They will help you achieve your goals and stay one step ahead of any challenges.

Also remember that, no matter what your long-term strategy, there's always room for improvements along the way. "My advice would be to take it in 12-year chunks," Dr. Abrams says. "Look how different this disease is now compared to 1981. The first 12 years were dismal. The second 12 were a complete change. Who knows what the next 12 will bring? With the progress being made, I think there's every reason to be hopeful."

Read "Game Rules" to help guide your long-term living strategies, and go over it with your health care team.

## Game Rules

**Nobody embarks on an HIV journey knowing exactly how to play. But the basic rules for long-term living are easy to follow—and it's never too late to learn them.**

- 1.** Be sure you're working with a health care provider who is easy to talk to and has a lot of HIV experience. If the relationship doesn't feel right, find a specialist you feel comfortable with.
- 2.** Long-term living with HIV often means making important decisions. Educating yourself about HIV and its treatment—and keeping up-to-date with the latest information—can make your choices seem less daunting, especially when talking with your health care provider. [AIDSmeds.com](http://AIDSmeds.com) and [poz.com](http://poz.com) are great resources.
- 3.** Talk with your provider about HIV meds proven to go the distance—not all ARVs have shown persistent safety and effectiveness in long-term clinical trials.
- 4.** Get the support you need, as you need it. Financial troubles, emotional difficulties, social isolation, abuse and drug use can hinder your well-being and can occur in HIV newbies and veterans alike. Your doc, clinic or nearest AIDS service organization can hook you up with the services you need.

(IVERSEN) JAMES PATRICK DAWSON



## The Lazarus Effect



When John Iversen, now 59, tested HIV positive in January 1986, he threw himself into AIDS activism, co-founding ACT UP/East Bay and a Berkeley needle exchange program. By the late 1980s, his CD4s had fallen to about 200. Observing that AZT (retrovir) taken by itself didn't seem to help people, he joined a trial of Compound Q, an experimental herbal therapy. His CD4 count climbed, but he developed rheumatoid arthritis that left him bedridden and he experienced severe bowel problems caused by cytomegalovirus (CMV) infection.

With a CD4 count of 46 in 1995, Iversen started a drug regimen of three NRTIs and a year later

added a double dose of a PI. He gained 50 pounds, stopped his CMV treatment and could finally get around without a walker.

After a decade on the same PI, Iversen has had difficulty keeping his viral load consistently undetectable with his current drug combo. He hopes that a switch to Prezista (darunavir) plus Truvada plus the new NNRTI Intelence (etravirine) will do the trick. He's had "no major side effects" on his current regimen, which he attributes to complementary therapy including vitamins, Chinese herbs and acupuncture. He also watches what he eats, does yoga and exercises regularly.

Though still on disability, Iversen works tirelessly as an advocate. He helps people with HIV in developing countries gain access to the treatments that turned his own life around, and he raises several thousand dollars a year for an orphanage started by HIV-positive people in Uganda.