Crash-Test Smarties

Even though many people have controlled their HIV for years, some can still hit detours like cancer or hepatitis. But with the right support, they don't run off the road.

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"Undetectable does not mean squat," says Sharon Wagner, 51, of Houston. The mother and grandmother has had HIV since 1987 and controlled it with meds almost from the start, but she has reason to be wary of her rosy lab results. In 2005, she was diagnosed with non-Hodgkin's lymphoma (NHL), an "AIDS-defining" cancer still common in the age of HIV combo therapy. Wagner says the cancer cure disrupted her HIV treatment and turned out to be (nearly) worse than the disease. "My gut was torn up with ulcerative colitis. It was hell."

Frustratingly, it's still unclear why lymphoma and other cancers are more common among HIV-positive people—even when meds have the virus under control. Nor is it clear why we seem to face elevated risk of cardiovascular disease (CVD), debilitating bone loss and organ failure. In an interview with AIDSmeds at the Conference on Retroviruses and Opportunistic Infections in San Francisco last February, Priscilla Hsue, MD, of University of California at San Francisco, said that scientists no longer hold HIV treatment side effects responsible for CVD among HIV-positive folks. Now, Hsue said, atherosclerosis (plaque buildup, or hardening of the arteries) is increasingly seen as a "disease of chronic inflammation, [and] emerging data say that HIV itself—even suppressed—is associated with chronic inflammation…[leading doctors to ask], 'Should we consider HIV itself a cardiovascular risk?'"

The persistence of these illnesses undermines the perception that HIV is now simply "manageable." We may not be falling prey to AIDS, but HIV has devious new ways to make us sick. Happily, outcomes for HIV-positive people and civilians are similar: Today our survival rates for NHL and anal cancer, for instance, equal those of negative people. But we experience multiple serious diagnoses much more commonly. Thanks to better HIV drugs, newly diagnosed people now lead almost normal lives, although living with HIV—staying on top of blood tests and taking drug combos day after day—remains tough. And now that the road has gotten longer, detours appear more often. How do we get back on track after unpleasant "diversions" like cancer, a heart attack, a hip replacement or hep C?

Wagner's cancer, she says, "[almost] killed me emotionally. Treatment was long and hard—seven days a week." What's more, her cancer drugs complicated her HIV care, dropping her CD4 cell

count, and she became resistant to her HIV meds. After starting a new combo and experimental immune reconstitution therapy, she developed colitis, requiring emergency blood transfusions. “And I was going through a divorce!” she says.

Meds for depression and anxiety revived Wagner’s spirits, and she found solace at home and church. “My spiritual path was strengthened through my faith community and family,” she says. The combo of support and chemotherapy worked: “The treatment has been a success, I am three years out and happy!”

Viral coinfections raise similar challenges for long-term HIV survivors. John Uehlein, 54, has been living with HIV since 1984, with hepatitis C (a leading killer of HIV-positive people worldwide) for longer, and in recovery from meth addiction for over a decade. After trying AZT and other monotherapies haphazardly throughout the ’90s, he didn’t start managing HIV until he got sober. His viral load has now been undetectable for years. He believes his hep C dates from before the viral strain was named. “I was in the hospital with ‘non-A, non-B’ hepatitis for 30 days back in the ’70s,” he says. In 2001, with HIV under control and a year of sobriety under his belt, he finally got a liver biopsy, which showed moderate (Stage II) disease. He was working as director of music at a Manhattan church and singing in the chorus at New York City Opera. “I had all this exciting work,” Uehlein recalls. “I was newly sober—I had enough on my plate.” So he postponed interferon treatment, which has a reputation for difficult side effects.

In 2006, however, a biopsy showed advanced (Stage IV) disease. Uehlein’s doctor referred him to a respected specialist at a leading hospital—and trouble ensued. “The doctor wasn’t there on the day of my biopsy, so two interns did it. Then I waited and waited—six weeks!” he says. At long last the specialist telephoned. “She said, ‘Mr. Uehlein, I don’t remember who you are, but I have to tell you, you have cirrhosis’”—severe scarring that damages liver structure and functioning. The hospital’s program also did not offer coordinated care. “I needed a psychiatrist who’d sign off on my ability to get through the treatment,” he says. Interferon carries a high risk of mood disorders—especially for people with a history of addiction and depression, like Uehlein.

Eventually he found a clinic with comprehensive services. (“I’ll never go back to a private doctor,” he says.) In a few weeks, after his first blood work, however, he was hospitalized. It turns out no one had checked for possible interactions with his HIV meds, and one of Uehlein’s drugs (the protease inhibitor Reyataz/atazanavir) was known to be potentially harmful for people with hep C. He had to stop all treatments. After six weeks he restarted interferon, then a new HIV drug regimen.

On the road again? Not quite. “I started interferon on December 17, 2006, my birthday,” Uehlein says. “My wish was that it would succeed.” But from the start he was plagued with blurry vision, memory loss and lapses in concentration. On February 1, at his therapist’s office, he had a seizure, landing him in the hospital again. The trigger: another drug interaction, this time with lithium, his antidepressant. The hospital kept him for six days, running millions of tests, he says, “to rule out everything else, just in case.”

On a new HIV cocktail and a new psych med, he ploughed ahead. “There was depression, yes. Fatigue, yes. Was I able to deal with it? Yes.” Uehlein’s pillars during his 15-month hep-C treatment were acupuncture, tons of sleep and food, and sobriety. “I went to a lot of [12-step] meetings,” he says, attributing the success of his treatment—he cleared hep C—to support from friends and generous self-care (he allowed himself to eat whatever he wanted). “Cut yourself breaks,” he advises. “Take cabs.”

Paul Bellman, MD, a longtime HIV practitioner in New York City, has guided countless patients through similarly treacherous rapids. Success takes courage, determination and psychological resilience, Bellman says, adding, “My challenge is to support these qualities [in each patient].” He acknowledges that battling for decent health care, as Uehlein had to do, can itself be harmful. “Building a support network and participating in support organizations can help,” he says.

Like Wagner and Uehlein, Paul Van Nies, 60, of Palm Springs, California, has hit roadblocks in his 30-year journey with HIV. Avascular necrosis (AVN, bone death from poor blood supply—disproportionately common among people with HIV) necessitated three hip replacements (one botched), leaving him with a pronounced limp and some pain. Two years ago, Van Nies had human papillomavirus (HPV)–related anal cancer, which he calls “really horrible,” including two surgeries. The cancer was especially frustrating—his immune system was running well and his HIV was undetectable at the time.

“The ravages of long-term HIV have taken their toll,” he says. “I tend to worry about when the next ‘event’ will be.”

Van Nies’s saga from disease to meds to side effect to surgery illustrates the sad fact that treatments essential today—in his case, anti-inflammatory steroids—may create problems later. “I had KS in the early ’90s. The radiation sores [required] prednisone.” He also needed high dose steroids during three bouts of *Pneumocystis carinii* pneumonia (PCP) in 1993. Such steroids have been shown to cause AVN in people with HIV. But Van Nies is also sure they saved his life.

Today, on his third HIV cocktail, he maintains an undetectable viral load and his CD4 cell count has climbed to 630. “I truck on,” he says. “I cycle and work out, eat well, do yoga, work in my garden and go forward. I try to be thankful for living.” He gives major credit to good friends and family, a terrific partner of 25 years (they married two years ago) and his much-loved cats, Buzzy and Betty.

Living long term with HIV might well involve further problems—cancers, complications or challenging coinfections. “On the one hand, the new generation of drugs has enabled us to treat our patients more effectively and with less toxicity,” Bellman says. “On the other, many patients suffer from persistent immune deficiency, something we have to address with new insights and therapies.”

Bellman, as it happens, is among a growing chorus pointing the finger at chronic inflammation. “[Its role] in cancer and other disease is a very promising area of research for HIV,” he says.

Tackling inflammation might help treat common HIV side effects such as lipodystrophy and other metabolic changes. Beyond that, it could be that inflammation actually causes the persistent immune deficiency that might promote damage from infections like HPV. “Recent data from HIV-negative women with HPV show that pro-inflammatory molecules in the mucosal tissue may be a risk factor for cervical cancer,” Bellman says. And a study in the November 1 *Journal of Acquired Immune Deficiency Syndromes* reported this ominous nugget: During a five-year survey, HIV-positive people with elevated levels of two inflammatory proteins, fibrinogen and high sensitivity C-reactive protein (hsCRP), had higher risks of death than those with low levels of the proteins, regardless of other cardiovascular risk factors.

Progress in treating inflammation among people with HIV, Bellman says, will shed light on treating many other diseases. “At a policy level,” he adds, “recent calls to decrease HIV research dollars relative to other medical conditions seem particularly shortsighted.”

Whatever is causing our ever-more-common detours—HIV med toxicity, chronic inflammation or the simple fact that we are living longer and, thus, are more prone to illness—what can we do? Van Nies has a suggestion: “Just happily stumble forward.” And hope researchers find new ways to catch us if we fall.

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