

# 'A Lot of Unknowns'

**Medical advances are helping many HIV patients live into old age. But that blessing presents its own unique set of tribulations.**

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**NEWSWEEK WEB EXCLUSIVE**

Sep 18, 2008 | Updated: 11:45 a.m. ET Sep 18, 2008

There was a time when Lee Chew was so sick, he'd lost all feeling in his lower body—forcing him to wear diapers and get around by wheelchair. At 6 feet 2 inches, the once-robust actor was a skeletal 135 pounds, with severe pain in his hands that prevented him from even holding a fork. It was 1996, nearly 10 years after his diagnosis, and AIDS was all around him: friends, lovers, even his doctor, all died of the disease. Funerals were a monthly ritual. "In a way, living through the AIDS crisis of the 1980s was like living through our own version of the Holocaust," he says. "It was a nightmare."

Chew slowly began to wake from that nightmare with the approval of a new antiretroviral drug, Crixivan, that would help nurse him back to health. Slowly but surely, he went from wheelchair to walker, walker to cane, and finally, back to the gym. Today, Chew, a New Yorker, by way of Roanoke, Va., is happy and healthy, tan and fit. At 59, he looks about 40. "I can be pretty vain," Chew jokes. "I like to make sure my pecs look good."

In reality, Chew worries about a lot more. He is a social worker for aging HIV-positive gay men, so AIDS remains a constant character in his life. And though he's healthy, Chew is getting older—which brings a whole new set of worries. His is the first generation to age with HIV. As he ages, there are changes in how his medications will interact. And doctors and researchers are only beginning to figure out what, exactly, that means.

What doctors do know is that despite infection rates that remain level, people over 50 now make up the fastest-growing segment of those living with HIV—part of the reason why the [AIDS Institute](#) this week announced Sept. 18 as national HIV/AIDS and Aging Awareness Day. It's perfect timing: between 1990 and 2005, local Department of Health studies show that the number of AIDS cases in people over 50 shot up by more than 700 percent—today, 35 percent of people with HIV are aged 50 and older, and 70 percent are over 40, according to the [AIDS Community Research Initiative of America \(ACRIA\)](#). A large portion of those, say advocates, are gay men. Some of these older patients are newly infected, while most are long-term survivors.

Researchers know that HIV and age make for a complicated balancing act—a convoluted interplay of the disease itself, natural aging symptoms and the side effects of antiretroviral medication that may enhance those symptoms. Part of the aging process is already about a loss of immunity. So the fact that HIV is an immune disease may be one reason why its sufferers tend to age fast, in everything from body changes to cardiovascular disease, says Dr. Richard Havlik, an epidemiologist and former chief of the epidemiology, demography and biometry laboratory at the National Institute on Aging, in Bethesda, Md. But patients can also be plagued by ongoing side effects of drug cocktails, which range from high blood pressure to neuropathy—a painful nerve disorder that causes numbness in the hands and feet. And they must often fight fire with fire: a medication may heal one ailment, but in many cases, it only causes another. "All of those are bonuses—the side dishes—to the main course of HIV," Chew says.

With multiple HIV drugs on the market, allowing for physicians to mix and match to limit side effects and resistance, the medical community can often only make educated guesses as to what causes a particular ailment: Is it the virus? The meds? Aging itself? "From a health care viewpoint, that's one of the great black boxes," says Stephen Karpiak, ACRIA's associate director of research and the author of one of the only comprehensive studies on HIV and aging. "And the reality is we just

don't know." Scientists didn't begin using the drug cocktails that turned AIDS from death sentence to chronic illness until 1996; prior to that, it was still considered a young person's disease, with everybody focused simply on survival.

Experts say that's not enough history to grasp the drugs' impact on the body, particularly in older patients. Clinical trials until now have been virtually nonexistent, and most big drug companies don't use older patients in trials—because of the possibility that those already at high-risk for disease would complicate the results. "It's very much to me kind of a good news-bad news situation right now," says Dr. Bill Stackhouse, director of the New York-based Gay Men's Health Crisis, the world's oldest AIDS-service organization. "The good news is that the meds are great, and people are living longer. But now there's a whole new set of issues to be faced."

Chew and his patients know that reality all too well. On a recent Wednesday in New York, Chew led an HIV-support group for Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE). The group regularly vents about doctor's visits, pill regimens and the laundry list of side effects that are becoming more complicated with age. For this session, Ernest Krysty, 61, has traveled from Connecticut; he says there isn't a support group closer to him. He describes the painful lesions on his stomach from the acid in his drug cocktail—12 different pills each day: six for HIV, and the rest for heart problems and lipodystrophy, a degenerative tissue disorder that redistributes fat, which commonly occurs in those being treated for HIV.

Another member of the group, Bruce Miller, 59, takes up to 20 pills on some days—and recounts the painful hip-replacement surgery he had to have last year. Miller isn't sure what caused the bone degeneration in the first place—as Havlik puts it, "there are a lot of unknowns"—but the procedure caused a hematoma that had to be surgically removed, resulting in nerve damage. During his rehabilitation, he was prescribed an antidepressant that he's now struggling to wean himself from. And now he needs a replacement in his knee, too. "It's sort of like a house of cards," Miller says softly. "The more pills you take, the more possibility for interaction. And as you grow older, there's more of a chance of that collision."

Chew himself has diabetes, high cholesterol and neuropathy—all ailments he never thought he'd be around to see. "Having been HIV-positive for so long, and lived through the earliest part of the epidemic, I think the notion was that it would kill us long before there was any question of any other physical ailments," says 53-year-old Mark Stewart of Manhattan. "Part of what's helpful about this group is that we share notes about ... all those things you never thought you'd have to deal with, because you thought you'd be dead."

Those issues, of course, extend far beyond the physical. Stigma related to disease and age—and, in many cases, sexual orientation, too—has been shown to cause depression and anxiety. (In a 2006 study, ACRIA found rates of depression in HIV survivors to be nearly 13 times higher than in the general population.) Many of those aging with HIV don't have social networks they can count on, either: gay seniors, who make up a big chunk of this group, are [twice as likely as their straight counterparts to live alone](#). "People with better social networks are more adherent to their meds, less likely to be depressed, and we know from the gerontological literature that those with better social networks live longer—outside of HIV disease," says Charles Emlet, a social worker at the University of Washington who studies the virus and aging.

In many ways, HIV-positive people over 50 are like guinea pigs, says Chew: they are the first to age with HIV, and the first to experience that process truly out of the closet. "With each step along the road, from the '80s to the '90s to now, every step has been a step in the dark," Chew says. "And there was always the thought that, well, this medication might result in heart disease, but if it keeps me alive now, then so be it." Sometimes a step forward can feel very much like a step back.

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