45 Years Later: The Strange Grace of Being a Long-Term HIV Survivor

45 years after AIDS was first reported, HIV long-term survivor Tom Duane honors loss, resilience, activism, and hope for ending AIDS.

June 4, 2026 By Tom Duane

The HIV community is about to mark a staggering milestone: the 45th anniversary of the first reported cases of AIDS in the United States. On June 5, 1981, the CDC's *Morbidity and Mortality Weekly Report* described five young gay men in Los Angeles with a rare pneumonia normally seen only in severely immunocompromised patients.

Forty-five years. That number feels almost impossible.

June 5 also marks HIV Long-Term Survivors Awareness Day, a day that exists because thousands of people somehow lived long enough to personally mark the day. That said, humanity really does create holidays for everything, although I don't see Hallmark cards to celebrate such occasions. But this day really matters, especially to folks like me who've been living with HIV since the dawn of the AIDS crisis.

Long-term HIV survivors are people who acquired HIV before effective treatments existed, before 1996 when protease inhibitors transformed HIV from a near-certain death sentence into a manageable chronic illness. Some survived because we had access to clinical trials. Some because we were stubborn. Some because fate rolled the dice strangely. Most still do not fully understand why we lived while others did not. I know I don't.

The moniker Long Term Survivors also includes folks who didn't acquire HIV, but were involved in the community of caring friends and family during the crisis. They may not have had the virus, but they certainly suffered alongside those who did.

Many of us survivors buried entire circles of friends before medicine finally caught up. When it did, for the most part, funerals for those far too young to die, ended.

Well, that's not completely true. There were still people at risk of dying because they had no access to adequate healthcare. And many people did not know their HIV status, because they didn't want to know. Perhaps it seemed to them that there was no hope for HIV/AIDS specific healthcare, or they were not provided adequate counseling and information. And then there were people tested without their knowledge or consent, who were faced with and shocked by this

diagnosis, internalized their status, and told no one. Yes, some were able to personally and publicly declare their “membership,” but many were not. Stigma kept a lot of people from being taken care of, a problem as persistent as HIV itself.

My memories of those early HIV days are in fragments. Hospital rooms with drawn blinds and “Danger!” signs on the door. Medical professionals dressed in hazmat suits.The antiseptic smell of wards nobody wanted to visit. Watching friends suffer terrifying weight loss, literally wasting away. Young gay men boldly wearing Kaposi’s sarcoma lesions like fashion merit badges. Coded phone calls from friends trying not to sound frightened. Memorial services stacked one on top of another until grief became a weekly appointment.

But somehow, we always found a way to laugh. Since the dawn of time, gay men have had a particular skill of using comedy against despair with surgical precision. Someone always had a biting joke in the waiting room, or made fun of the terrible hospital food (I remember one friend complaining to a nurse: “Sweetie, it smells the same going into me as it does coming out of me!”) That same friend also always insisted on flirting with medical staff while attached to three IV lines, a catheter, and a pulse oximeter.

And the memorial services were not morbid affairs, but creative celebrations, imaginative and extravagant. If you think queers are good at throwing parties, you should see our funerals! It was a dark time but honey, we decorated that darkness with sarcasm and sequins.

Then came the mid-1990s and combination therapy, protease inhibitors. Suddenly, people who had planned funerals started panicking about finances and retirement instead.

Survival sounds noble, but it feels different from the inside. Surviving long term means carrying ghosts of friends forward into decades they never reached. It means attending weddings they should be attending with you. Watching technology evolve from pay phones to smartphones while still hearing the echo of someone’s laugh from 1989.

There is also a sad irony many long-term survivors speak about in hushed tones: after outliving the plague years, we are old enough to once again watch friends die.

Not from AIDS now. Well, not always. Sometimes it’s cancer. Heart disease. Addiction. COVID. The ordinary brutalities of time. Survivors who once thought we escaped death entirely are discovering we merely postponed our turn in line.

That reality can feel especially cruel because many of us spent decades believing we would never grow old. Some did not save money because they assumed they would not need retirement. Some never built careers because the future felt fictional. Some, like me, have PTSD when reading obituaries.

Modern patient advocacy in countless diseases owes a debt to early HIV activists. Those heroes who chained themselves to buildings and draped a massive condom over Jesse Helm’s home, etc., fought like hell because their friends were dying while politicians debated morality. We created

activism that transformed our culture.

Long-term survivors built communities (what author Armistead Maupin calls a “logical family”) when governments looked away. We cared for one another when families refused. Groups like ACT UP and TAG (Treatment Action Group) forced the world to pay attention. Groups like HousingWorks created supportive housing and services. Patients demanded faster drug approvals, humane treatment, and scientific urgency. “Nothing about us without us.”

That history matters. Our history matters.

It matters because younger generations deserve to know HIV is not just a pharmaceutical commercial featuring smiling, attractive, multi-cultural people at picnics and dinner dates. It is also courage, rage, fear, mourning, love, terror, endurance, and an entire generation shaped by loss.

This June 5, HIV Long-Term Survivors Awareness Day asks us to remember all of it. And to remember that, with all the medical advances: U=U, PrEP, the many choices when it comes to the prevention and care regarding HIV, the AIDS crisis is not over.

Yet, I remain full of hope that we will end AIDS. (Yes, my drag name might be Polly Anna.) And I think the key to ending it will be the community coming together to help each other. Just like always.

Forty-five long years after those first reported cases, despite everything our community has been through and the challenges we’re facing now, I still think that life is a beautiful gift. I’m grateful.

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http://beta.docker.poz.com/blog/fortyfive-years-later-strange-grace-longterm-hiv-survivor