



The Long Haul

Former New York state Senator Tom Duane shares the lessons he learned as a long-term survivor of HIV in a blog post. Below is an excerpt.

May 18, 2026 By [Tom Duane](#)

I turned 71. Some people make a sour face when they find out I'm an Aquarian, and I really can't understand why. We're the most fun, passionate, caring beings, all with a little quirkiness thrown in. What's not to love?

I'm not sure I ever thought about getting to this age. Youth has a way of keeping those thoughts at bay. My HIV diagnosis was also a big factor when it came to thinking about the future.

As optimistic as I've always been, I didn't plan on becoming a long-term HIV survivor. Nobody did. When I was diagnosed in the '80s, the phrase "long term" wasn't even on the table. The future was a dark, vague concept, filled with the very real possibility that I wouldn't be around to see it.

And yet, here I am. Older. Still positive. Still standing. Just like Elton John! (Well, he doesn't have HIV, but you know what I mean.)

Surviving HIV long enough to age with it is both a privilege and a strange, unadvertised challenge. Medicine did its part, brilliantly—and continues to, thankfully. Life, as usual, got complicated anyway.

For a long time, the goal was simple: Stay alive. Make it to the next year. Then the next. When effective antiretroviral therapy arrived, survival shifted from long-shot miracle to genuine expectation. And now, according to the Centers for Disease Control and Prevention, people with HIV who are diagnosed early and remain on treatment can expect near-normal life expectancy.

That sentence looks neat on paper. Living it is messier.

Aging with HIV means I carry my history in my body. Years of older medications. Chronic inflammation. Trauma that never made it into my medical chart. Many long-term survivors experience higher rates of cardiovascular disease, bone loss, kidney disease and cognitive changes compared with HIV-negative peers, even when the virus is well controlled. Not to mention the fun stuff that comes with aging in general: high blood pressure, liver disease, cancer risks, etcetera.

Turns out, survival has consequences.

A lot of people I started this journey with didn't make it. I carry those friends with me in my heart. That devastating kind of loss doesn't politely fade with time. It compounds.

Getting older already thins your social circle. Aging with HIV can hollow it out. Some long-term survivors face isolation due to stigma, fractured families or decades spent in survival mode instead of relationship-building. Studies consistently show higher rates of depression, social isolation and drug and alcohol misuse among older adults living with HIV.

For me, it's an awkward grief. I'm grateful to be alive and angry about it in the same breath.

It reminds me of the longstanding rally cry from our community: "All I want is a cure and my friends back." I first heard that phrase decades ago, and it hits me with renewed ache today. There are so many people I miss. And why was I among the lucky ones to survive?

Heaven knows, I've earned the right to complain about pill organizers, insurance paperwork and doctors who are younger than my diagnosis. I have to laugh at the absurdity of surviving a global crisis (more than one!) only to have arguments with a pharmacy app.

There is no medal for stoicism. There is, however, a beautiful freedom in saying, "This is hard" without apologizing—and a strength in moving forward despite it being hard.

Aging looks like adaptation. Radical acceptance. Advocacy, always. Choosing rest without calling it weakness. Asking better questions. Building community where none existed before.

It looks like surviving long enough to redefine what survival means.

If you're aging with HIV, you are not a medical anomaly or a cautionary tale. You are evidence. Of science. Of resilience. Of the deeply human ability to keep going, even when the road map keeps changing.

You weren't supposed to be here. Me neither. And yet, here we are. Getting older and doing it in style.

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