Privilege and Price

In a blog post titled “The Privilege, and Price, of Aging With HIV,” POZ contributing writer Shawn Decker reflects on his struggles to survive with the virus and shares thoughts on an after-life. Below is an edited excerpt.

November 11, 2024 By Shawn Decker

As I approach age 50 next year, my overall health is on the front burner in a way that it hasn’t been since I started on HIV medications at age 23.

It’s not that my health hasn’t always been a focus. When my parents found out their second son had the rare bleeding disorder hemophilia, it impacted our entire family. It wasn’t long before I contracted hepatitis B via the contaminated blood products that would also gift wrap HIV and hepatitis C. But while my health was a focus for my parents, as a kid, I did everything I could to ignore my medical résumé.

For a few years in elementary school, I played baseball. As a teenager with HIV, I got into music. I refused to read the T-cell leaves and weathered the stigma storms. I also found a measure of peace in living day-to-day without the existential pressures that come with planning for a future. Things really changed dramatically when, at age 20, I discovered my love for writing, put up one of the first HIV websites in 1996 and was soon a contributing writer for POZ.

Even then, however, I didn’t take my health seriously. It was more like putting a “Kick Me” sign on the back of the grim reaper’s cloak at school. Everyone laughed, everyone high-fived. But a lot of my biggest supporters in those early days of speaking out were worried. Recently, my wife, Gwenn, and I were going through some old boxes, and I found a stack of emails I’d printed.

One was from POZ founder Sean Strub. In it, he said the office was worried about my health.

His email came after I’d returned home after a short attempt decades ago to move to New York City. That’s because soon after I got home, I had a two-month-long bronchial infection. Sean and my friends at POZ were worried because, given my history with prescription medication, I was as scared of side effects as I was of HIV.

After falling in love with Gwenn—who I wouldn't have met had I not opened up about HIV—I finally had to face my virus. It finally caught me sticking that sign on its back, and it was pissed. So was I, actually. I'd just moved from my parents' place to Charlottesville, a safe 20 or so miles away. I wanted to focus on my music and take a break from HIV. That's a laugher, huh? "Hey, HIV, chill while I get my synth pop on."

My only shot at survival was to start taking HIV medications. The side effects sucked, but my T cells rebounded. Gwenn had moved in with me shortly before that big change. Part of not being able to put off starting meds was not being able to pretend I was healthier than I actually was. Within two years, she saw me at my worst health and my best.

With more T cells and motivation to educate than I'd ever had before, Gwenn and I were off to the races, educating as a couple about HIV, stigma and healthy relationships.

Denial was a safe—albeit lonely—place where I couldn't dwell on a future of any kind for too long, because that future certainly involved an AIDS-related death. Still, close calls with hemophilia expedited my making peace with my mortality, to the credit of my mom's wise teachings in what had to be some really scary moments.

I actually loved the thought of an after-life. Living without a body marred by medical mayhem seemed kind of cool. Still does, actually.
