The Privilege, and Price, of Aging With HIV #NHAAD

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

September 18, 2024 By Shawn Decker

Another National HIV/AIDS Aging Awareness Day (September 18, officially) is here and, alas, I am one year closer to age 50. These days 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 a rare bleeding disorder in 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 resume.

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 at age 20, when I discovered my love for writing, put up one of the first HIV sites online in 1996 and was soon a contributing writer for POZ Magazine.

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 Gwenn and I were going through some old boxes and I found a stack of emails I'd printed.

One was from Sean Strub. In it, he said the office was worried about my health. I was doing my first T-Cell Labtest Contests, which became more joyous affairs after I started HIV medications. In the beginning, the results were always some form of not good. Stephen Gendin guessed the closest and I mailed him a signed (by me) picture of me and Danny Bonaduce, who I randomly met while having lunch in NYC with one of my friends and editors at POZ.

"Tough way to get a gig."

Danny Bonaduce and Me, Circa 1997

That was Danny's advice when I told him I was from Virginia and writing about my experiences growing up with HIV.

Maybe it was, but I was so happy that I'd found my footing. My purpose. Sean's email came after I'd returned home after a very short attempt 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 the virus.

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 to Charlottesville, a safe twenty 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 synthpop on?"

My only shot at survival was to start taking HIV medications. The side effects sucked, but my t-cells rebounded. Shortly before that big change, Gwenn had just moved in with me. 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. For the first time in my life, I thought about the future as being more than a few years if I was lucky. We got a lot of attention- check out our Media page. It was a thrill to be the kind of story for a stranger out there with HIV that I wish I'd seen after my diagnosis, when the doom and gloom of the late 80s, pre-med media on AIDS forced my strategic retreat into denial.

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.

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To read the full version of this, head over to ShawnandGwenn.com - just be sure to come back to POZ!

I'm hopeful that I'll be writing more- and more casually- soon. The dread of this ritual is reading what I wrote, for the reasons mentioned above. Often I won't finish something because of that- I'll stop editing and just banish it to Drafts. That writ, one of the best articles I've ever tapped out is about to be published, and I can't wait to share that. By "tapped out", I mean printed and re-printed, discussed with Gwenn, tears over realizing how paralyzed I've been by writing... one of the damn loves of my life that helped save my life.

On that teaser, I'll wrap this thing up. Thank you for reading and allowing me the space and time to tell you what's up on National HIV/AIDS Aging Awareness Day in the year 2024, where more kindness to ourselves and each other is so desperately needed.

Positively Yours,
Shawn
