Long-Term Survivin’ and Thrivin’

Just read a moving conversation between longterm survivors Mark S. King and Tez Anderson, and it got me thinking...

August 19, 2022 By Shawn Decker

Mark S. King caught up with Tez Anderson, founder of Let’s Kick ASS (AIDS Survival Syndrome), at the International AIDS Conference in Montreal and it’s a conversation worth reading. Any longterm survivor can relate to the wear and tear of HIV and the side effects that come with some of the medications, which have improved dramatically over time.

Mark and Tez also articulate how the “psychic weight” can impact someone with decades of living with—and losing loved ones to—HIV.

Like them, I was diagnosed with HIV in the mid-80s. I was spared one of the worst aspects of the epidemic, those early days when the memorials would not stop. I decided to open up about my status in 1996, around the same time that combination therapy was changing the game for those with access to decent medical care. The option of survival had arrived... I remember sitting in my room after a bad night of bowling, depressed and wondering what the hell I was going to do with the rest of my life.

I was 20 years old. In an instant I went from don’t even think about a future to having one. I use to call that moment my so-called mid-life crisis. But this Summer I turned 47 so the math no longer holds up, thankfully.

Thinking that I’d make it to 40 wasn’t so much about the news of antiretrovirals creeping into my HIVault, where I never sought out updates on the virus, it was from the confidence of having lived a decade with HIV. All I knew was that I needed something to do, and arriving at the thought of opening up for the first time about my HIV status was exhilerating because it was such a surprise to me. As a result, there wasn’t much of a decision to be made and I was off to the races.

Undoubtedly, my HIV diagnosis changed the course of my life. As did opening up about it all.

Fortunately, my health turned around in 1999 when I started on HIV meds. Life was very busy throughout my 20s- I met Gwenn and we educated about being a “sero-diverse couple”. Which could be very tedious in the pre-UEqualsU days. “Are you scared?” “No. Shawn and I use condoms everytime, and we know how to effectively use them.” “But are you scared?” I’m proud of how we handled things, with sensitivity and understanding. I know I wouldn’t know all I do about HIV if I hadn’t have contracted it. I take great pride in my “work”, which is really just sharing my

experiences with HIV. It's been the honor of a lifetime.

In recent years, I've come to the realization that I could be around until the age of 80, which has necessiated a focus on other areas of my well-being, mental health in particular. I've also been exercising more and eating better. Some parts of this wellness journey have been more consistent than others, but I'm glad I embarked on this. It's made 2022 much more bearable.

I gotta say, though, even though my prognosis is good, I still understand that tomorrow is not guaranteed. An interesting side effect of taking care of myself in my 40s has brought me closer to the healthy attitude that sustained me in the post-diagnosis pre-opening up teenage years, when the weight of a future wasn't something that hung heavy over my head. Back then I found some peace in not having to engage in the rat race of junior high and high school… I knew, even then, that I was able to experience my life on a different level because all of the rules get turned upside down when a life-threatening illness is part of the equation.

Living one day at a time is, once again, where it's at for me.

Like Mark and Tez, I don't see a future without some involvement in HIV. Spending more time on this blog is where the intersection of personal health and community involvement is for me right now. I'm being as open as I can be about the loss of my mom and sharing the life lessons, laughs and memories she provided. The feeling I have right now is close to the feeling I had when I sat at my computer in my parents' house and typed away about HIV for the very first time… I didn't really know who would see it, and in a way that was secondary to opening up the disclosure floodgates.

It was freeing. A lot of the safeguards I'd built up through the first decade of living with HIV had outgrown their usefullness. In the last few years, I've been tearing down other defense mechanisms. One of those, ironically, was built in part by my HIV educational work. I never wanted my story to be a "woe is me" tale- those don't get people to consider HIV testing, or help see people with HIV as the viable members of the dating pool that we are if you're lucky enough to meet a single one. So for years I downplayed the depression and some of the harder aspects because those bits were time suckers, and I didn't see any educational value in talking about it.

Probably because I wasn't ready to acknowledge that it was still affecting me, just not wrapped around an early HIV diagnosis.

Blogging is a full circle moment right now. There's also a beautiful feeling that connects me to those last couple of years when I lived safely under my parents' roof in my early 20s, and I was typing away in my bedroom. I know they were proud of me for taking control of HIV, but I also know they were fully prepared to dedicate a room in their house to me for however long my life would be.

Not sure there's an overall theme to this entry which, admittedly, I've sat down and written on a few different times. It's like eating a snack and wrapping it back up. It gets uglier with each stab at it. I know it's an acceptable strategy for snacking, but for writing it's pretty bush league… but if I

go back and read too much of this I'll probably delete it. So if you've made it this far, that makes two of us!

I just know I'm very thankful to be a longterm survivor and I'm thankful for the lessons that my challenges have taught me, and continue to teach me. Like those disconcerting months before I opened up about HIV, when I knew something was off but I had yet to put my finger on it, the last few years I've been weighed down... the weight of an uncertain future felt similar to my pre-disclosure angst, only with the added layer of being older and wondering if your best work on all fronts is behind you. Our minds can turn our proudest moments against us if we let it.

In focusing on my wellness, I'm being kind to myself. I'm also able to be there in a more meaningful way for the people in my life if I'm the best version of myself that I can be, and accepting that those goal posts move. Which is okay. Focusing on and allowing myself to simply have a good day is, well, simple... but it's also achievable more times than not.

The present can be far too easily squeezed to death between the past and the future. So here I am once again, doing one of the things that literally helped save my life after my HIV diagnosis: I'm doing my best to not think about the future and simply focus on having a good day, or the best bad day possible.

Positively Yours,

Shawn

© 2026 Smart + Strong All Rights Reserved.

http://beta.docker.poz.com/blog/longtermsurvivin