Real Stories of HIV Stigma and Its (Often Surprising) Outcomes

A collection of experiences regarding so-called friends and health care professionals

November 29, 2018 By Alicia Green and Trent Straube

Each December 1, World AIDS Day places the epidemic in the global spotlight. This year, we wanted to look at one of the most persistent challenges people living with HIV face: stigma.

Stigma simply refers to the negative attitudes and beliefs (often erroneous ones) about people living with HIV. In short, it's prejudice. And it can be deadly. Because of stigma, many folks are afraid to get tested. Some skip their meds and doctor's appointments. Stigma can keep you from reaching your fullest and happiest potential in other ways too. Maybe you have been given plastic utensils at a family function or been ghosted by a potential love interest after disclosing your status. Perhaps a physician or coworker treated you differently because you are HIV positive.

You're not alone. We asked members of our POZ Personals community to share their stories about HIV stigma and then to explain its lasting outcome—for example, whether the experience changed their viewpoint or imparted some wisdom. Below is an edited selection of stories and outcomes. You can read a related collection of stories about dating and hooking up here and here. Some of these people use their real names; others prefer their screen names or initials (because of, you guessed it, stigma). Every one of them also offers a story strength. Even when faced with unfair discrimination, these people with HIV remain resilient.

SAMUEL B.

Story "Back in February 2008, I was diagnosed with HIV by my family physician. He referred me to an [infectious disease] doctor that he claimed to know and who would tend to my future needs. [When I first met the new doctor] I noticed that he really didn't want to touch me without doubling his rubber gloves. Also, he wore a surgical mask and other gear as if he were going into surgery. This was my first appointment as an HIV-positive patient. I felt that this was the standard process until my second appointment—when he sent in his assistant who mentioned that he would no longer be able to see me due to his lack of HIV experience. I [assumed] he and his whole office were afraid to even get close to me."

Outcome “I have moved on to experience the best doctors I could ever imagine. Every situation is considered a learning experience for me. People are who they are. All one can do is try and be the best person one can be. Hopefully, they’ll see the good within in order to better themselves.”

MICHAEL T.

Story “I tested HIV positive at age 29 in the mid-’90s. I lived in small-town Middle America. I made the mistake of informing the few guys that I had sex with (instead of giving their contact info to the health department). Unfortunately, the news of my infection traveled like wildfire. That was July. Come Christmas, I looked forward to a big Christmas party that an older gay couple hosted at their home every year. It was very popular. I remember making small talk at the party, but people weren’t as friendly to me as in the past. Then this one snarky guy asked me very loudly, “Sooo are you in diapers yet?” and the room exploded with laughter. I wanted to crawl under a rock. I quietly said no, then snuck out of the party and cried on the way home. After that, I quit frequenting our local dance bar and chose to go to a little gay pub that had more of an older, more understanding clientele. Sadly, the internet was even worse. I was told by one guy that I wouldn’t be positive if I wasn’t a promiscuous whore. I told him, ‘For your information, I was in a monogamous relationship when I contracted HIV.’ Things have gotten better over time, but you still find uneducated people out there.”

Outcome “Less than a year after the Christmas party ordeal, I met my partner who was also HIV positive, and we have been together 21 years. He has been my rock and has taught me to not take things so seriously and to enjoy life. My advice: Love and accept yourself and find people who love you for who you are. Also, the book The Subtle Art of Not Giving a Fuck by Mark Manson has helped a great deal.”

DAVID V.

Story “Texas overall is very conservative, but rural West Texas is even more closed-minded than the rest of the state. I am fortunate and blessed enough to have an extremely good HIV doc in Midland/Odessa, but I would never think about finding a family doctor in the small town I live in for obvious reasons. I have shared my status with a couple of local friends and my employer, but it’s a challenge to really trust anyone in this small town. When I was first diagnosed, it reminded me of ‘the old days’ when gay people were bashed or their homes were vandalized. I could see this happening in the town I live in if the wrong people found out.

My biggest challenge, health-wise, is finding a dentist who is HIV-friendly. I’m sure there are laws pertaining to discrimination against HIV-positive individuals, but who really wants to go there? I’ve had to go to a few specialists for thyroid, vision, etc. all referred to by my [infectious disease] doctor, so his referral made it a little easier. My meds all come through mail order. But when I need certain meds quicker, I use a pharmacy in Odessa so as to avoid our local pharmacies in the town I live.”

Outcome “I’m still looking for some silver lining or a better way to live with the stigma. I know a lot

of it is within and with the relationships I build with people. Probably more people would accept and respect my HIV-positive status if they knew. It’s the strangers and the people I don’t have a close relationship with that I worry about.”

MICHAEL VARGA

Story “For those of us infected in the 1980s, the stigma was monstrous. People feared that any contact with me—or with anything I touched—would lead to disease. Some friends stopped hugging me; some family members stopped visiting. It was very hard. In 1996, I needed to see my dentist in Philadelphia, and I was living in southern New Jersey. [During] previous trips to the city, I had stayed with my friend, Jason (not his real name), whom I’d known since grade school. As far as I knew, Jason and his wife did not have an issue with my HIV-positive status. However, this time, Jason told me his wife was no longer comfortable having me in their home, especially because she feared I would “somehow transmit the virus to their two young children.” I was crestfallen. I mentioned to Jason [how the virus could and could not be passed], but he said his wife was adamant. That was the end of a lifelong friendship. We have never communicated since then.”

Outcome “What such an experience teaches you is how resilient you are. I learned that I am stronger than HIV, stronger than AIDS. I also found out who was in my corner and who was eager to abandon me. Such life lessons are priceless. While Jason disappeared from my life, other friends stepped up. With no treatments available back then, those friends knew that my demise could be just around the corner, and they wanted to spend as much time with me before I might be gone. Such a stance meant so much to me in those dark, challenging days. This year I have been living with the virus for 35 years. Back in the 1980s, I could never have expected to last this long, so there is only gratitude for a life that has been enriching and full. I remember all of those who didn’t get the chance to grow old, and I live with more gusto because of their loss.”

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