



Native Stories of HIV and AIDS in Honor of those Living and Passed

In 1987 I learned that I was infected with HIV. At the time it didn't affect me. I did not take it seriously. I was in denial; I thought that it was a white man's disease. While living in San Francisco in the 1980's the death rate for AIDS was pretty high. Many of my white friends, sex buddies and neighbors were dying. I remained in denial; in fact I refuse to take HIV medication for 18 years. It was not until I contracted Hep C that I decided to take medication for HIV while in treatment for Hep C. I have been on medication for five years. I'm healthy and Hep C free. Nevertheless, I'm still in denial about HIV

I had a friend who was the life of the cool urban parties. I grew up with him since the 1st grade. His mother knew my mother. We used to go swimming together in the river with our created rafts and sharing our lunch with each other. He always knew the latest dances, and up on the fashion trends. Coming from a small town our knowledge of the big city was limited. So following his spirits, off to Los Angeles he went. It was not until five years later, I ran into him at a local bar. He was visiting in town for the holidays. It was great to see my long time friend. It was not until shortly after I moved to Los Angeles, that he informed me he was positive. I was shocked. I was angry for a while. Eventually he passed away at age 26, he was buried in a \$3,000 Donna Karan suit. Yes, he did blaze a trail for me. Because of him, my partner of 17 years and I both live in Los Angeles, we take care of ourselves and our health. I give thanks to my friend for bringing awareness to me. He inhabits the hallway of my mind, as he leads down the hole into another world.

Early back in the early 1980's, I was sitting in my mother's office (x-ray department) at the Indian hospital. I remember my mother's boss and co-worker coming in and making horrible comments about an Indian man having AIDS who needed an x-ray. The Native man was the first patient at the Indian hospital to be admitted with an AIDS diagnosis. My mother's boss and co-workers did not want to touch the Native man. They begin saying horrible things in regards to him being a fag and being infected. My mom's boss requested that my mom conduct the x-ray.

I told my mom not to be afraid, and to use precaution, i.e., gloves while performing the x-ray. I told my mom that she should not be afraid because one day it could be one of her children. In 1994 I contracted HIV. Today I'm living with my T-cell count of 78 and an AIDS diagnosis. My mom loves me. She no longer fears individuals who are infected. She has since educated herself. AIDS have slowed things down, but have not stopped the progress in my Red Circle.

I have a friend who is dealing with HIV, as well as other people, I've talked to. The emotional pain is overwhelming. Words can't describe how sadden I am. I can't put



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it to words what an individual is going through. For several years while in a program, I visited a hospital during Christmas time to offer my love and compassion to patients infected/affected by HIV/AIDS. Just seeing and having conversations with people living with HIV/AIDS was an impacting experience. It also gave me a more in depth understanding. I now have an open heart and mind.

There was a friend I knew who had HIV. I never had sex with her. Nor did she allow me, even though I furnished her with drugs. I could never understand. Was there something wrong with me? This was something that bothered me. It continued for about six months. Then I didn't see her for two months; eventually I went over to her apartment looking for her. I ran into her daughter and she informed that her mother died of AIDS. I was shocked. Still to this day I thank her for not allowing me to have sex with her. I'm grateful, since her death, I have educated myself regarding HIV/AIDS and STD'S.

Native two-spirit individual, my good J. I'll always remember and honor you and your life. Thank you

How HIV/AIDS affected my life. I have known two of my sexual partners who were living with HIV. It brought fear and uncertainty to my life and future. Having that fear has made me more cautious of my sexual lifestyle. Knowing what the end result could be if I don't take care of myself. I've taken a moment to educate and empower myself.

A Lakota medicine man once told a colleague of mine that "when a person comes to you for healing, it's them who heals you". During the eight years I provided direct services under a Ryan White CARE Act Program, I had the privilege to experience this healing first hand. What I witnessed was that, no matter how tough the circumstances, my clients always found a way to rise above it. This was a testament to their strength and courage – that even when the future seemed to be a dim light in a darkened tunnel, the will of the human spirit forges its way through and makes the necessary adjustments to survive. This has been a great lesson for me. I have come to realize that there is great healing in love, compassion, forgiveness and letting go - but most important, in giving. My work and association with people living with HIV/AIDS has enriched my life and I will forever be grateful for their humanity. There are many stories to tell of the eight years as a Native HIV case manager. It is the following that I chose to share.



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I remember the day I was assigned to my youngest HIV positive client, a little five year old girl, who soon after her birth lost her mother from complications of AIDS. As an infant she was caught in a custody battle between her father and grandmother, a situation that was ignited by the fact she had been estranged from her father since her mother's pregnancy. At the time she was assigned to me, she was living with her dad and had just returned from a summer visit with her maternal grandmother. This little girl was typical in nature – full of energy, extremely friendly and very astute. Yet, like many individuals living with HIV/AIDS, this little girl was living with a secret. This was a secret that her father and grandmother had encouraged her to keep, one that would protect her from the harsh cruelty of a misinformed world. Just like the cruelty that Ryan White had experienced in the 1980's from his school and community.

Though my little client was in many ways like other children, her secret would always set her apart. I remember how her father and I sat down with her before her first day at school to explain what to do if she was injured while playing during recess – the normal playground injuries such as cuts and scrapes from falling on the asphalt. She was aware that the only person on campus that knew of her secret was the school nurse and that she could depend on the nurse to help her. The thing that was so amazing about this little girl was her ability to understand her situation and yet not let it get in the way of being a kid. She was amazing. Even at a young age, she had the ability to adjust to her situation and rise above it. One of my fondest memories of her was after returning from a summer visit with her grandmother, she ran into my office with great excitement! An excitement that children display when they are told they are going to Disneyland or getting a new bike. Instead, her excitement was telling me of a great achievement. She had mastered the skill of swallowing her meds, which meant she would no longer have to take that awful tasting liquid. A couple years later, her doctor put her on a drug holiday because it appeared she was showing signs of antiretroviral drug resistance.

It has been ten years since I have seen this little client who is probably grown up to be a beautiful young girl. I often think of her: how is she doing managing her meds and her teenage years. What I will always remember was her childlike mind in a world filled with medical appointments and antiretroviral treatments. Her childlike manner was unrestrained by the voice of reason, cynicism and the fear of failure. Instead, she was filled with childlike delight, marked by innocence, trust and ingenuousness. These virtues shield her from the realities of her HIV status and allowed her to be a child. This truly was a lesson of the power of the human spirit in its purist form--a lesson that has left a significant imprint on my life.

In the late 1980s my mother (a nurse) worked in an Indian clinic. Word was out that this clinic was "friendly", so Natives with HIV would drive from all over the area to be treated at this clinic. She said she would triage the waiting room, pick out the boys



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that were really sick to see the doctor right away. She would promise the other patients the first available appointment with the young doctor (very cute). With the boys that were under age and dying, she would let them know that she had to contact their parents. They would protest, but she explained that since they were minors, she needed to notify them. Once she made the call, within 12 hours, the families would start to arrive. Once reunited, the families would cry and beg their sons to forgive them and let them pray for them as they made their journey to the next world.

In the 1980s one of my dear friends was diagnosed with AIDS. The doctor thought he may have been HIV-infected for many years prior to his diagnosis. He was an up and coming San Francisco artist from an East Coast tribe. He maintained a healthy diet of low fat, protein health shakes and was consistent with his medication. He always wanted to see the Southwest. So that summer, we took him on a road trip down I-5, east on I-40 through the Mojave and finally into the Arizona mountains. We took him to edge of the North Rim of the Grand Canyon and from there to the Diné reservation, Canyon De Chelly, and Monument Valley. Took pictures standing out in the desert, like the Marlboro ads. Even got pulled over by tribal police because of a burned out tail light. Then in the fall, he got sick and never got better. After work we would drive to San Francisco General Hospital's Ward 86 to see him and visit with his family. We gave him a Pendleton blanket, he admired once, for his burial. His obituary listed his death from pneumonia.