I Chose to Live and Love

After being challenged physically, spiritually and mentally by HIV, Simba Say raises awareness about living with the virus.

May 23, 2022 By Simba Say

The 2013 holiday season wasn't the most memorable. I had a few friends from grade school over. We hadn't seen each other in years. One of them looked at me and said, "You look skinny."

Have you ever heard the saying, 'Seek humility or you will find it?" In that moment, I found it. I wasn't accepting that something was wrong, and I wasn't honoring the God in me who was dropping hints here and there saying, "Simba, go to the doctor!" I thought I was just battling my dirty 30s, but I was dying. I just didn't know how, and I didn't have insurance to find out.

In late December, my mom found a clinic that could help. It was called the Good Faith Family Clinic. My appointment to get my results was on January 3. I knew this day would be life-changing. I thought I had cancer of some kind. I never thought it was going to be HIV/AIDS.

That damn mind game of denial quickly turned into reality. It wasn't what I thought it was going to be—it was a totally different path. My mom and dad were in the waiting room. And here I was with someone I had only just met, and I was spiritually dying in front of him. I was shaking so bad, he asked if there was anyone I could talk to. I called my sister.

My parents were sitting in the waiting room gripped by fear. Fear of what was going on with their baby boy. My mom's birthday was the next day. How could I tell them this now? This was not the memory I wanted aligned with her special day.

I broke down. I couldn't even get the words out to my sister. I had to hand the phone to the doctor, and he had to tell her. He handed the phone back, and all I could say was, "Hey."

Her response gave me the strength to walk out of that room and tell my parents that there were no results yet, more tests had to be done.

Instantly, I was thrown back into a totally different closet. I'd spent my youth in denial, trying to hide the fact that I was gay. Being in the closet was not fun. Living a double life and the impact it had on my mind and soul was not a feeling I thought I would ever experience again. But here I was, feeling it.

When emotions are high, intelligence is low. Someone introduced me to a scientist who said he could cure me. Yes, you read that right. He said he could cure me of HIV, and I would be negative again. But there were some conditions. One was not to tell anyone. Another was that I wouldn't take my HIV meds, my antibiotics, my antifungals—everything that was prescribed to me by my HIV specialist. I agreed and went into another closet. It tore the family apart.

I was challenged physically, spiritually and mentally. Physically, my diagnosis was grim. Not only was I HIV positive, my CD4 count had dropped to the low 50s and I was diagnosed with Kaposi sarcoma, the cancer associated with an AIDS diagnosis. My viral load was 2.2 million. I also had thrush, candidal diaper dermatitis, herald patch, body wasting (I was 45 pounds lighter than I am today) and 17 cancer lesions across my face alone. I went into a anaphylactic shock with my first med cocktail, the cocktail I took when I chose to live. I was on a hospital bed, looking up at my mom and dad at each side, crying, saying it wasn't supposed to be this way. Yet there we were, at what we thought was the end, saying goodbye to each other.

Spiritually, I grew up in the church. I ran from the church when society cast the cloud of judgement toward my sexuality. When I was so sick, I reached back out to the church, and the dark sides of religion I experienced were terrifying. I was taken to a church where a healer did a prayer over me in front of many people. I started crying and had snot running from my nose, and the healer told me it was the demons coming out of me and to let them out. I also had to walk through my house with the healer and her priest. They had me burn incense and drink some cocktail they made, and they told me I needed to throw away a piece of art on my wall because it was evil and demonic. It was an artist's drawing of Our Lady of Guadalupe from Mexico. I said no. I knew it had a spiritual meaning, but it also held a personal meaning to me.

I didn't realize that the cure treatment from the scientist was a lie. Mentally, I was battling the acceptance of my new life—a life with a disease that at times made me hate myself. I felt so ugly inside and out and was at a point where I wanted to let go. The darkness was taking over. I started watching videos of beheadings, burnings and drownings. I found myself attracted to things that never gave me a cause to live, never motivated me or inspired me. I hoped that I'd eventually be led into the light, and I'd find my place in the circle around the flame.

But guess what—I won. I beat AIDS. I beat depression. I beat the dark side of religion. I chose to

live, I chose to love, I chose to spend a year finding a million reasons to love myself so that I could start A Million Reasons to Love and help the kids at the Children's Bereavement Center of South Texas. I chose to allow my mom and dad to show me another side of religion, one that is about love, exemplary of God's word and one that rises above the darkness. I was able to see that by being a part of my mom's children's ministry, Wally and Sniper. I chose to give modeling and acting a try, and it seems to be taking off. More importantly, I have been joining hands with those fighting stigma and raising awareness about living with this disease.

What three adjectives best describe you?

Loyal, honest, passionate.

What is your greatest achievement?

Going to the White House for an LGBTQ Pride reception and briefing. Going public with AIDS.

What is your greatest regret?

Not accepting my sexuality at a younger age. It kept me from living my life to the fullest. I lived in fear and not fully proud of who I was. I needed to let go of religious judgement.

What keeps you up at night?

The way I have been treated since going public and the assumptions about being in a better place than I really am. People don't understand the mental side of living with HIV.

If you could change one thing about living with HIV, what would it be?

Battling stigmas and fear. I love educating others, but some people can't seem to understand U=U [Undetectable Equals Untransmittable]. A reporter once referred to me as contagious.

What is the best advice you ever received?

To learn to let go.

What person in the HIV/AIDS community do you most admire?

Greg Louganis.

What drives you to do what you do?

To help educate people and prevent others from going through pain and judgement. Also, I feel we need to be celebrating where we are at and the advances that have been made.

What is your motto?

“If I give up now, I will be back where I started. When I started, I was desperately wishing to be where I am now.”

If you had to evacuate your house immediately, what is the one thing you would grab on the way out?

My beads/bracelets. Everything else is replaceable—but not those. They each have a story, whether it’s something my mom gave me, something I bought while traveling or given to me by someone special or important.

If you could be any animal, what would you be? And why?

A lion. They are beautiful animals and protect the pride. They are strong and powerful with a gentle, playful side. They only eat to survive, not devour all they can.

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