Why Not Me?

Long-term survivor Lori King stopped being angry about being HIV positive and started educating others about the disease.

September 13, 2021 By Lori King

The woman came out of the office and called out my number. She was plump, with blonde wavy hair and was wearing a floral wrap dress. I followed her into the small office. It was bare-bones: a desk, two chairs, a window. The walls were a dingy white, and black file cabinets lined the far wall. I sat down on the hard, wooden chair, glancing down at the legal pad on her desk. A number was written at the top of the page; farther down, it read “results: positive.” I could feel my heart stop. My mind started racing: Was that my number? Maybe that was from the last patient. No, it isn’t mine. I must have read it wrong. She pulled her chair closer to the desk and moved the pad away from my view. She started saying how she was sorry to tell me that my results came back positive. I thought, You’re sorry? It’s not happening to you! You didn’t cause this—I did!

I am 27 years old, two years sober and have just been given a death sentence. I couldn’t hear anything she said after the initial news. My body froze; my arms and legs were numb. My mind was telling me to get up and walk out, but I was dead weight in the chair. As I stared out the window, everything in my peripheral vision became blurred. It was as if I was witnessing what was happening from somewhere else. Her lips were moving, but she sounded miles away.

Finally, she stopped talking, and I was present in the room again. We stood up together as she handed me a large manila envelope, looking at me with her sympathetic brown eyes. I felt compassion for her. It’s one thing to receive the news of having a terminal illness but to be able to give the news as part of your job is something I will never understand. As I left the office, my friend Dennis was coming out of the office across the hall. We came together to get our results. He looked down and saw the envelope in my hand. When I looked down, his hands were empty.

The people I got high with were getting sick. My friend Ginger was in the hospital with AIDS. I had gone to see her and talk to her before I decided to get tested. I was in her hospital room when I started to get thirsty. I asked her if there was a soda machine around. She offered me half of her can of soda. It was 1987, and people didn’t know much about AIDS. I hesitated for a moment, knowing she had drunk from the can she was offering me. Then I reminded myself, If I could share needles to get high and not care about the risks, I could share a can of soda. I needed to walk the walk. If I wanted to receive unconditional love, I had to give it as well. I took a sip from that can and never regretted it.

The day I found out I had the virus I went to a 12-step meeting. The last thing I wanted was to drink over this. My friends were dying, and I was the only one who got clean and sober. I felt as though I was going to jump out of my skin in the meeting.

I saw some of what my friends were going through, and I wanted to buy myself some time. I wanted to get tested before I had any symptoms. It felt as though I was looking at my life in fast-forward. I was terrified of this disease because it strips you of everything. The physical deterioration was horrifying to watch: the weight loss, the sunken face, hair loss and emaciation. Then there is the feeling of contamination: being hospitalized in isolation, people afraid to touch you. My biggest fear was dying alone.

It was a dark and rainy Friday night. I walked into the hospital alone and took the elevator down to the basement. Staring at the floor numbers going down, I reminded myself to breathe. My body was shaking, but I wasn't sure if it was from the dampness of the night or nerves.

Stepping off the elevator I entered a dimly lit hallway. It had a medicinal feel to it, with bare beige walls and a tile floor and fluorescent lights above. I could hear the echo of voices as I was walked toward the end of the corridor. A few people were gathered around a coffee urn. After they left, I fixed myself a cup of coffee and walked into the 12-step meeting for people with HIV. It was a warm and inviting room with comfortable reclining blue chairs and blue carpeting. Some people acknowledged me with a smile and a nod, yet they kept their distance, giving me a feeling of trepidation. No one had started speaking yet. I found a seat in the back and pretended to read a pamphlet. I was nervous. I needed to find other people in my situation and see how they coped with this disease while staying clean and sober.

Much of the room was filled with guys; there were only two other women. As the man in the front of the room started to share his story, I could identify with most of what he was saying. Then there was a break, and when we resumed, there were shares from around the floor. I struggled throughout the hour to put my hand up and introduce myself. I was terrified. My mind was saying to raise my hand and get it over with, but my arm wouldn't move. I felt paralyzed with fear.

Finally, with about five minutes left, my hand sprung up. I introduced myself and talked about being newly diagnosed. The man who was leading the meeting gave me the best feedback I ever received. "You have two choices: You can lay down and let this disease swallow you up and die, or you can do everything you have planned for the next 20 years now. It's your choice!" I knew he was talking from experience.

When the meeting ended, I got a few phone numbers and found people very welcoming. I found out later that they are skeptical of new people who enter the room because HIV is such a stigmatized disease. They wanted to know that I was one of them and keep it a safe place. I felt like a weight had been lifted. I had found exactly what I was looking for.

My friend Nancy was the only person who knew about the can of soda with Ginger. After the meeting, she and I sat in her car to talk. I had a shake with me that I placed in the console of her car. As I was talking about my fear of being alone with this disease, Nancy picked up my shake and took a sip from it. That meant the world to me! I knew I would not be alone through this.

Every day when I take my meds, it reminds me that I am dealing with a chronic disease. I am also aware that these pills have kept me alive for over 30 years. Whenever I start to get sick, panic sets in. There is a room in my mind where I go to watch a movie about all the ways my disease will take me out this time. This movie is constantly playing, and I feel like I have no control to shut it off. No one knows about this room because I don't talk about it. I am afraid of what you will think of me.

When I'm feeling this way and someone sees me and asks how I am, I respond, "I'm OK." I don't tell the truth because I convince myself they are not interested or will think I am nuts. But when they say, "You look good," an invisible anger is unleashed within me.

I'm not really angry at you. I'm angry at myself for not saying what I am feeling. Holding in that anger is not only damaging mentally but physically as well. Stress affects my immune system, and suppressing my feelings causes stress. So the next time someone asks me how I am doing, I'll say, "Not too good. It's been a tough day" and leave it that. I can walk away without being angry, and my health doesn't have to suffer.

I stayed angry with my disease for about two years. I thought staying angry would make my disease disappear. I was wrong. My anger only pushed people away, not my disease. I decided to surrender and accept I was HIV positive. I wasn't going anywhere, and neither was my HIV, so I decided to become educated about it. HIV was put in my life for a reason, and I wanted to find out what that was, turn it into something useful.

I began by reading some theories about where HIV started and how it appeared. I started listening to visualization tapes and gave it shape and color. I would meditate on small purple jellybean-sized shapes swimming throughout my body. They were harmless, just looking for a place to live. My question for HIV was always the same: "What do you need or want from me?"

My belief was that the virus wasn't hurting me, that it wanted to help me so that I could help others. Since I joined a 12-step fellowship, my recovery is always about helping others. So why couldn't my HIV help build my experience, strength and hope, just like my addictions? I took the opportunity to speak to a high school health class about living with HIV. I also took a peer education training class and held a safer sex workshop for young people. I shared about it in my 12-step meetings. I was feeling useful when I talked about HIV. I became a camp counselor for 3- and 4-year-olds dealing with the same disease. Those toddlers showed me courage I couldn't see possible before.

I have been HIV positive for 36 years, and it has changed my life forever. I see things I would have never noticed until it came into my life. It has given me the opportunity to meet amazing people, be able to say goodbye to friends who were dying and experience life to the fullest. I still get scared when I get sick, and some days are better than others. But if I have helped one person on this planet because of what I have been through, then it has been worth it! I no longer ask why me, but why not me?

What three adjectives best describe you?

Compassionate, honest, loyal.

What is your greatest achievement?

Finding a better life with HIV in it.

What is your greatest regret?

I didn't enjoy being a kid more.

What keeps you up at night?

Nothing! I sleep like a baby!

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

The stigma.

What is the best advice you ever received?

This was told to me when I was first diagnosed: I can either allow my disease to swallow me up and kill me, or I can do everything I have planned for the next 20 years in the next two years.

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

I would say my biggest role model was Elizabeth Glaser.

What drives you to do what you do?

My inner strength and my HIV. It taught me to live life to the fullest because you never know when you will take your last breath.

What is your motto?

"No mud, no lotus."

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

My sobriety coin.

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

A horse. The have a gracefulness and beauty that I always enjoy being around.

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