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New York, New York
Living with HIV and Hepatitis C

In 1991 I was told that I was HIV positive and I had two years to live. Twenty three years later I'm 61, living alone (my partner of 25 years passed six years ago), lonely and not living in the neighborhood I once lived in. What keeps me going? I'm a Peer Educator, activist and occasionally work as a consultant. My down time is spent with my three daughters, a few childhood friends and my brother and his family on Long Island.

But most of the time I'm with friends from the HIV/AIDS community. Though I have the "4 H's"—hepatitis C, high blood pressure, high cholesterol and HIV, my main health issue is menopause. Menopause deprives me of sleep, gives me day and night sweats and mood swings so I can no longer wear silk or a heavy winter coat. Living on social security means the lifestyle I once had is gone. Depression lives with me now. My body is changing, I'm losing my hair and I am too tired to give my apartment the attention it needs.

But at the end of the day, I'm blessed to be still here. My T-cell count is 1000 and I'm undetectable, I'm not living in shame. Since I was diagnosed, my family and friends were told. My late partner and I were tested and told on the same day we were positive. Having a partner who was positive shielded me from much of the ugliness of the world. Together we volunteered and worked in the community. We also spoke out and told our story in the media, as a cautionary tale and hoping to educate and raise awareness that AIDS affects older Americans of all kinds. I love the work I do in the community and the friends I've made as well. But once I arrive home the problems walk in with me and the impact of living with HIV surrounds me. It is the story too few people know about a disease that is now presented as "manageable" and no longer a death sentence.

I deal with hair loss, leg pain, lack of money and I am living in a neighborhood in which friends from Long Island won't visit. I reminisce with old friends and family and look through my albums filled with vacation, events, outings and my childhood.

For the past 20 plus years I have worked as a speaker, consultant, volunteer, health educator, advisor and had people cry on my shoulders. Whenever I spoke at a conference or church I would get a few people who would state "its not my problem." Unfortunately, it is everyone's problem.

Because of our reckless behavior in the past (including myself), many “baby boomers” are now living with HIV/AIDS, hep C (and A, B), herpes, mental health issues and drug addictions just to name a few.

Until you have a complete physical with your primary care doctor you are not aware what’s going on with yourself. I caution people including a good friend of mine not to wait until you are seeing and feeling symptoms. That’s a sure indicator you have a health problem.

Regardless if you were born with a silver or plastic spoon in your mouth, have a successful career or unemployed, a genius or not, HIV/AIDS and hepatitis C affects everyone. Whether you are aware or not, you know someone who is living with these diseases. I gave a close friend’s father condoms and he was 84. We need to deal with reality and dispel the myths about aging and the behavior and sex lives of older people.

We are living longer and more active than our parents were at our age. My parents’ generation drank, my generation was drugs, sex and rock and roll. Being HIV positive is not a doomsday sentence for me. But my entire life changed. Sometimes for the better. Going to the doctor(s) every two months, taking medication, losing my partner of 25 years from liver cancer stemming from hepatitis C and receiving SSD benefits at the age of 40 was NOT in my future plans when I was 30! I am blessed to have three daughters, family and friends who are very supportive. But what if they weren’t? Where would I be? How would I be living?

We all think at one time or another “it isn’t my problem.” I too was one of those who was glad when someone had a crisis or problem and it wasn’t me. The year 1991 changed my way of thinking and living. Education, visits to your doctor, condom use, discussions with family and friends are some of the ways you can help stop the spread of these health issues. Now it is my problem! Please do not let it be yours!

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