

Living in 2019 Asbury Park with HIV

Barbara's Story

Our reporter met with Barbara, an Asbury Park resident who's been living with HIV for over twenty years. "Over twenty years" may seem like a vague period of time for such a critical event but she had HIV before her official diagnosis in 1999. Her HIV (human immunodeficiency virus) story begins with her diagnosis. She really doesn't know how long she's had it.

She was pregnant with her fourth child, at age 40, in 1999. At that time a standard test given to all expecting Mothers was an HIV screening. Hers proved positive. Her fourth child (her second daughter) was born HIV-free because she was delivered via C-Section. It is actually the delivery process that infects a new born. Unfortunately her first daughter was not so lucky. She had been born four years earlier when the HIV screening was not standard procedure and she was infected; Barbara didn't know. It was when she discovered she had the HIV virus that she also then learned that her first daughter was also HIV positive.

Barbara had been living a drug addicted life style in Red Bank, Asbury Park and New York City. After she was diagnosed with HIV she spiraled downward. She was given five years to live and told only 2 or 3 would be good years. As her drug use escalated she became homeless and she and her Mother went different ways. She was living in parks, abandoned houses and anywhere she could find shelter. She lived that way for ten years losing custody of her children to DYFS.

The change to her life came in 2008 when she was arrested for stealing copper. This is a felony. But it was her Judge who may have saved her life. He told her to get clean or face prison. She could not face going to prison so she got clean. At 47 she was clean long enough to get her kids back. She'd been thinking all this time that being clean on weekdays would be enough. She planned to start using again on weekends. Sound incomprehensible? She explains that it is drug addiction thinking. However, once she got her kids back she realized she did not want to lose them again. She's been clean ever since.

When Barbara was diagnosed with HIV she was classified as disabled, mentally disabled. That is a double edged sword. Barbara had always worked one job or another. After her diagnosis she gets a disability check every month. But she can't pass a background check so she can't get a good paying job. She has no credit rating and a criminal record. So how do you survive with so little going for you? Barbara relies on her close knit family.

It's always been nearly impossible to find an apartment. Still, she found an owner renting an apartment and lived in it on Sunset Avenue for twelve years. It recently became uninhabitable but she was able to find another owner renting an apartment. With her good history of paying her rent for twelve years she was able to secure the new place. Her check only covers half her rent and nothing else. Luckily for her she's got three of her children and a young grandchild forming a secure family unit who share expenses.

Barbara is lucky also in that she has been undetectable. That means the viral load in her system is minuscule and it's hard for the diseases that attack a person with HIV to take hold.

She currently takes medication and feels (and looks) great. She gets healthcare from the VNA on Main St. She eats healthy and gets lots of exercise riding her bike around the city.

She tries to explain what being told you have five years to live does to a person. She says it 'breaks' you. Why not escalate your drug use? Why not live a risky life? What does it matter? You'll die in five years anyway. This is the way thousands of folks lived in the 1990s and early 2000's. Then she adds there are folks who have other issues that are magnified when they are also told they only have five years to live.

She also talked about the stigma of living with HIV or AIDS. She says people always ask "How did you get it?" This question is worse than hateful. It is rude and insensitive as well as totally irrelevant. What does it matter? The question triggers that stigma. Barbara has never been married. She's had lots of 'get high' buddies. Now she has lots of buddies. She sympathizes with her friends who will confess to being homeless and even drug addicted but will NOT confess to having HIV or AIDS. She points out that you see ads for medication for high blood pressure or diabetes but not for AIDS.

We asked about living with HIV or AIDS in Asbury Park. She says the city's gentrification is making it harder to find affordable places to live. Most of her friends have no cars and walk. The only grocery stores in walkable distance are expensive and their products are not all she would prefer. There are few, small affordable Mom and Pop shops. She can't afford to shop or eat in Asbury Park. The Boardwalk is way too expensive.

Then she hailed the good institutions in Asbury Park for folks with HIV and AIDS; The Center, the great city parks, the VNA and the Family Success Center. She also complimented the Beach Badge program (started by resident Lisa Cramp) which pays for badges for residents of limited means.

Barbara has been HIV positive for over twenty years but does not have AIDS. She says she is at peace with her situation and treats her HIV the way she would high blood pressure or diabetes.

Reporters Note: HIV and AIDS are two different stages of the same disease. When diagnosed HIV positive it means you have the virus in your system but you exhibit no symptoms. When you have AIDS the virus has begun breaking down your immune system and you exhibit symptoms. Barbara wants to remind readers that the AIDS virus is not transmitted via drinking straws or toilet seats. Medical professionals encourage everyone to be tested for the virus. Although this suggestion may bring eye rolls from many, there are thousands of people who have the virus and don't know it.