Live to Tell

Hepatitis C advocate Patricia Shelton shares her love for life

October 9, 2017 By Tim Murphy

No one would say that Patricia Shelton has it easy. The New York City resident, 64, is living with both hepatitis C virus (HCV) and HIV, financial constraints and a stressful housing situation (the landlord of her Harlem apartment building won't move her to a unit that isn't plagued by earth-shaking noise from the tenant below).

She has survived heroin addiction and the loss of her partner of 25 years. She knows she smokes too much and should exercise more. She gets lonely and depressed.

But at the same time, nothing can stop her from loving life and cracking a one-liner like the hard-boiled dames in the 1940s movies she loves so much. She is also obsessed with the Kennedy family.

"They were our royalty," she exclaims. "I have 10 or more books on the Kennedys. Jack and Jackie. Of course, Ethel was jealous of Jackie." An artful beat. "I just wish we could go back to that time when it comes to the presidency."

She brings that effervescent chattiness and sense of humor along with her to work every day at Settlement Health, a community health center where she has been an HIV/AIDS and hep C peer educator for nearly a decade. On top of that, she's on numerous advisory boards, including those for New York State's AIDS Institute and the Positive Women's Network. And she cuts a stylish figure around town.

"I love to dress up," she says. "I have five pairs of cowboy boots, including snakeskin. Growing up, I didn't want to be a cowgirl—I wanted to be a cowboy."

The setting for that growing-up was Roosevelt, Long Island. "Hometown of Eddie Murphy and Dr. J!" Shelton notes. "I come from a sheltered world: mother, father, brother, sister, dog, house, church, school." When Shelton married young and had three daughters, it seemed she'd be replicating that life. But she did an about-face when she left her husband at 26 and moved with her daughters to Brooklyn.

It was 1980, and Brooklyn was down in the dumps, far from the trendy yuppie haven it has become in the past 20 years. "In my family, you didn't move to Brooklyn, you moved out of it,"

says Shelton. “But to me, it was an adventure, and my kids loved it. Every weekend, we’d take the subway to different museums and parks. It was our Disneyland.”

Eventually, she met Keith, the man who would become her life partner of 25 years. But he also introduced her to heroin. “Before him, I was the one who would ask for grape Kool-Aid at a party,” she laughs. While in detox in 1991, she tested HIV positive. “Right around the same time as Magic Johnson,” she notes. Keith tested positive for HIV as well. “The doctor told us we had two years to live. I told him, ‘I’m going out kicking and screaming.’”

She and Keith spent the ’90s on methadone, which she calls “liquid handcuffs,” and volunteered for various AIDS groups, including GMHC. “We made phone calls and went to Albany [the New York State capital] to lobby.”

Shelton started the early HIV medication AZT in 1995. In the late ’90s, she and Keith started working as peer educators. The times were all right. They’d spend a month of each winter at Keith’s parents’ large house on the beach in Barbados.

Shelton learned she had hep C in 2002, the same year her mother passed away. Although her diagnosis was upsetting, she understood all too well that baby boomers like herself—people born between 1945 and 1965—have the highest HCV rate in the United States.

She tried what was then available for treatment but stayed on it for less than a month because she couldn’t handle the harsh side effects. “I was throwing up, headaches, and—mind you—I was also going through menopause. So I said no way.”

Newer hep C treatments have high cure rates, and studies find that older people are as likely to be treated successfully as younger individuals. Unlike the old interferon therapy for HCV, the new medications have mild side effects and are well tolerated by people of all ages.

As both an HCV advocate and a peer educator, Shelton knows that hep C treatment is once again something she needs to seriously consider, so she is now weighing her options carefully. “I’m not scared anymore of hep C treatment,” she adds.

Shelton has every reason not to be afraid of trying again to get cured of hep C. The new drugs—which are known as direct-acting antivirals because they attack HCV directly—are taken for about two or three months and have cure rates above 90 percent.

In contrast, the old interferon therapy lasted a year, required weekly injections and cured only about half of those who tried it.

The new drugs are so effective that groups of people who did not respond well to the old treatment—including African Americans, people living with both HIV and HCV, and people with advanced liver disease—can now usually be cured. There is little reason to delay treatment.

There are several medications to choose from, including coformulations that include a complete

combination regimen in a single pill.

Various factors need to be considered before choosing a regimen, such as HCV genotype, viral load, past treatment experience and level of liver damage (fibrosis or cirrhosis).

After a long battle, Shelton's partner Keith died of liver cancer in 2008. She took the loss hard. "We were together until the day he died. I'd always had someone to go through things with."

Yes, she says, she still has her children, siblings (she's the oldest of seven), cousins and friends—but no one can replace Keith. Plus, most of her family is on Long Island, and her relatives don't often visit her in Harlem. "I'm a widow who misses being in a relationship," she says.

So things aren't always easy, but Shelton nonetheless insists on putting the zing in her life however she can. She's especially excited about a cruise around Italy and Greece she's taking with childhood friends this summer. She also still travels to Barbados and visits family in North Carolina.

"As one of my girlfriends says, 'For being broke all the time, you're always traveling!'" she says with a chuckle. She loves to shop with family and friends.

And she can always disappear into her beloved old movies. She especially loves those with Bette Davis and Joan Crawford. "My mother was a housewife, so I liked strong, independent women," she says. "And they knew how to dress back then."

She has some tips for others living with HIV, hep C or other chronic conditions. "Keep your doctor appointments," she insists. "I grew up in a family where we didn't wait to go to the doctor until something fell off."

She also tries to eat well—lots of oatmeal, poultry and salads—even though she's not fond of cooking. "I'm not my mother," she says.

Most of all, Shelton knows that life, with all its challenges, must be savored. "You only have one life, and each day is a blessing, so don't wait. I overdosed five times, so I know God brought me back for something."

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