One Down, One to Go

HIV-positive singer and activist Sherri Lewis is cured of hepatitis C.

February 18, 2016 By Tim Murphy

The first thing you notice about performer and activist Sherri Lewis is her laugh—a wonderful cackle that usually follows one of her hilarious, self-deprecating remarks about her topsy-turvy six decades of life. But on this October day in Los Angeles, where Lewis has lived since 1999, the laugh is full of pure joy.

The reason? It's the last day of her three months of taking Harvoni, a daily pill to treat the hepatitis C virus (HCV) she's been living with since she was 17, and now her hep C is undetectable. "It's a pretty historic day for me," she announces.

Her 12-week follow-up test results confirmed her joy that day—she is cured of hep C. In fact, 96 percent of Harvoni takers who also had HIV were still hep C undetectable, hence considered cured, at the 12-weeks-after-treatment mark.

Lewis lived a long time with both HIV and hep C. Among the many lessons of her life, which in the '80s included the highs of showbiz and the lows of addiction, is the fact that you can live with both viruses if you work with a doctor and take care of yourself—especially today, when HIV has long been treatable and hep C can be easily cured. The road to today for Lewis has been a long one. She grew up in a comfortable New Jersey suburb, singing and dancing professionally in New York City on TV shows for children, and managed by her dad, who sold women's accessories out of his office in the Empire State Building.

"He'd say, 'If I can sell a handbag, I can sell talent,'" Lewis recalls. "And he was right." From an early age, Lewis knew she had the stuff to make it big—an exuberant stage presence and a terrific voice. "I took my work seriously even as a kid," she says. "No one ever told me, 'Stick to your day job.'"

But her early 1970s Jersey adolescence was also troubled, marked by the breakup of her parents' marriage and sexual abuse by someone close to her. In her teens, seeking solace from the pain, she tried injecting heroin. Of course, none of that stopped Lewis. At 18, she moved to New York City to study acting, where she joined a Ukrainian dance troupe and lived in the East Village, then one of the city's most dangerous neighborhoods.

"You never found your car the way you left it," she remembers, laughing. "Once a knife was pulled

on me, but thankfully nothing happened." Was she scared? "I had nothing to compare it to except Jersey, which I hated," she laughs. "I was a pop kid, so I started making my way to clubs," like the rock hangout Max's Kansas City, where Lou Reed got turned on to her stage presence. Soon enough, she was in an all-girl punk band called Mande Dahl. "We had songs like 'Kitchen Bitch' and 'Glands Out of Control,'" Lewis recalls with a fond chuckle. "I wore Barbie-doll plastic earrings."

But shadowing her fun was bad health news. As early as 17, "I felt terrible," Lewis recalls. "I was falling asleep all the time, burping a lot with a really rotten-egg taste to it." A doctor tested her liver and told her she had hep C—or what was then called non-A, non-B hepatitis. (Hep C wasn't discovered until 1989.) "I must have gotten it from my early experimenting with needles," Lewis assumes. "The doctor said, 'You can die from this, so you can't drink.'"

She didn't drink for a while, but then she did again. Then came marijuana and the '80s. Lewis and her new boyfriend, Zecca Esquibel, started a band called Get Wet that caught the attention of disco producer Neil Bogart, who was looking to shift to pop. "He said to us, 'We're going to make you the next big thing' and brought in Phil Ramone to produce us."

The result was the doo wop-sounding "Just So Lonely," which in 1981 made it to No. 39 on the Billboard chart and got the duo a spot on American Bandstand. With her good looks, bright voice and vintage style, Lewis was poised to become a pop darling à la Madonna or Cyndi Lauper.

But then came cocaine. "It was the '80s, and everyone thought it wasn't addictive," laughs Lewis. "I didn't have to buy it. It was brought to us in the recording studio, mountains of it, cocaine and champagne." Then, while on a promo tour in Europe, the white powder she requested turned out to be heroin. "A little sniff here and there, and I was knocked out."

It was all downhill from there. Lewis and Esquibel broke up amid tension that the producers wanted her as a solo act, which Lewis says made her "so paranoid" she couldn't act on it, choosing instead to be bought out of her contract for $5,000 and playing small local gigs. "I got lifted out of a lot of cakes at Gay Prides by muscle boys," she laughs.

But by 1983, she was completely addicted to heroin and living in the dark in her West Village apartment because she wasn't paying the rent or electricity. She abandoned the apartment, sold everything she had and went to the East Village, "copping drugs and hanging out in abandoned buildings and luncheonettes."

Eventually hitting rock bottom, she "crawled into a detox," which led her to nine months in a Roman Catholic state institution in New Jersey. "I left there shell-shocked," Lewis recalls. Thus began her slow climb back to sobriety and recovery, attending 12-step meetings on St. Marks Place in the East Village and working at the boutique of the iconic pop-punk fashion designer Betsey Johnson. A year later, a friend introduced her to a Boston musician. "He was so cool, salt-and-pepper hair, everything was perfect." The two got engaged. "I thought, oh my God, I'm going to have kids!"

But all around Lewis, longtime gay friends and fellow recovering injection drug users were getting sick with a new disease called AIDS. She got really scared when a female friend contracted it. “I saw her with wasting and dementia. That alarmed me even though I felt perfectly healthy. I was the queen of aerobics by then.”

When she visited a doctor in a Boston suburb to get a blood test for her marriage license, she also requested an HIV test. “He said to me, ‘Don’t worry about that, nobody tests HIV positive here, this is Massachusetts.’” Turns out, the first HIV test the doctor ever gave—to Lewis, on April 12, 1987, her 33rd birthday and three months before her wedding day, with the invitations already in the mail—was positive. (Lewis believes she got HIV sexually, but she’s not completely sure.)

“Thank God I had the 12-step program,” recalls Lewis, “because I knew how to pray. I dropped to my knees, and it’s a miracle that I didn’t pick up drugs again.” Happily, her fiancé tested negative. And though he was devastated to learn Lewis had HIV, the two still married and spent seven years together, though Lewis admits that her HIV diagnosis killed their sexual spark. “I felt too uncomfortable in my skin.” (They remain good friends, though, as do she and Esquibel, who’s still in the downtown New York arts and music scene.)

During those Boston years, she also began seeing a therapist, whom she continued to see for the next 12 years, until she moved to Los Angeles. “My therapist once said to me, ‘I thought I was going to help you die,’” she recalls, “‘but all you ever wanted to talk about was life.’”

And Lewis now had a fierce will to live. She worked for several years as a counselor and speaker for the Harvard AIDS Institute. She then found a similar job at the University of California, Los Angeles. After effective treatment for HIV came along in 1996, she finally went on it in 1998 and has been on it ever since. She has never had a major complication from HIV. She credits following a macrobiotic diet, along with her 12-step meetings, social network and hot yoga, with keeping her healthy all these years.

But there was that pesky matter of hep C. For years, Lewis was adamant that she would not go on any of the existing therapies with their harsh side effects, such as nausea, exhaustion and depression.

Then, in late 2014, the U.S. Food and Drug Administration (FDA) approved Harvoni, which contains the direct-acting antivirals sofosbuvir and ledipasvir. The med, along with the FDA approval of Sovaldi (sofosbuvir) in late 2013, signaled a major breakthrough in hep C treatment. The new drugs achieved unprecedentedly high cure rates with none of the old side effects. At that time, Lewis had stage 3 fibrosis, meaning that her liver damage was advancing.

Lewis and Judith Currier, MD, her longtime doc, agreed it was finally time for Lewis to take the plunge and get into a Harvoni study. “We’ve been walking this path together for a long time,” Lewis says of the two of them. “We’re like a Lifetime TV girly movie!”

But then they hit a snag: Pre-treatment testing showed that she had some kidney problems, which she and Currier attributed to Lewis’s several years on Truvada (tenofovir/emtricitabine), an HIV

drug that has been linked to kidney damage. Lewis first had to switch to a new HIV regimen.

Lewis finally started her 12-week course of Harvoni this past summer. “I had a little nausea and headache the first month only, so I took it with oatmeal,” she says. “But I actually kept thinking, I can’t believe they came up with a hep C drug where you can take it and function. It’s not like the older drugs, where people really suffered. It’s amazing, even though it’s expensive.” Harvoni costs about $1,125 per daily pill, or $94,500 for 12 weeks of treatment.

“But it’s cheaper than treating liver cancer or having a liver replacement,” Lewis continues. “I’ve seen people die from hepatitis, and once my HIV was under control a long time, it still scared me that my hep C was untreated for so long.”

lewis has strong advice for other folks considering going on hep C treatment: “Go for it. You’ve got to push to get it covered. My co-pay alone was $3,000. Since I also have HIV, ADAP [the AIDS Drug Assistance Program, a federal/state program via the Ryan White CARE Act] picked up my co-pays—what a blessing.” (Lewis has also received help paying for her insurance plan from AIDS Project Los Angeles.)

With her hep C now cured, Lewis is doing what she does best—thinking about how to get the most out of life. She’s been caring for her elderly mother, whom she moved to a facility in Los Angeles so they could see each other daily. “I didn’t want my mother to bury her child,” she says proudly. “I can see how what I’m doing now is the right thing.”

But what Lewis really wants to get back to is what she has done best since she was a little girl, which is performing. “I need to be singing!” she exclaims. Last April, she did a fundraiser for Project Angel Food, which delivers meals to folks in Los Angeles homebound with HIV/AIDS or other disabilities. She brought down the house with a heart-stirring rendition of Stephen Sondheim’s “Being Alive,” preceded by her tale of learning she had HIV in 1987.

She’d also like to write a memoir. “This story hasn’t been told,” she says. “A hetero Jewish white girl pop singer who had an actual moment with celebrity and success, then the downhill slide, then the success of staying alive and healthy right to this stage in life.”

She does have one more goal. “Beating HIV,” she says. “That’s the next step.”

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