Faith, Healing and AIDS

At 60, Rae Lewis-Thornton reflects on living long term with HIV.

November 14, 2022 By Alicia Green

From an early age, Rae Lewis-Thornton has faced adversity. Her childhood was far from perfect. Born to parents who used drugs, she endured abuse and experienced trauma. But Lewis-Thornton never stopped looking for the light at the end of the tunnel—even after she tested positive for HIV in 1987.

“By the time I was diagnosed with HIV, I had lived 10 lifetimes,” says Lewis-Thornton, a 60-year-old author and HIV advocate from Chicago. “But I had resilience. I kept looking for a better way. I thought something was wrong with me, but I never gave up.”

Lewis-Thornton was a 24-year-old political organizer in Washington, DC, when she was diagnosed. She felt as though she had finally gotten her life together and was following her dreams when suddenly everything changed.

In response to a blood shortage, in 1987, Lewis-Thornton organized a blood drive at her job. About a month after donating blood, she received a letter from the American Red Cross informing her that something was amiss and asking her to come in. That’s when she learned that she was HIV positive.

“They didn’t know what to tell you back then,” she says. “The woman kept saying ‘You don’t have AIDS. You only have HIV, and you may never get AIDS.’”

So Lewis-Thornton left the Red Cross building believing that her condition would never progress. “I remember saying, ‘Lord, I can handle HIV, but don’t ever let me get AIDS,’” she recalls.

Lewis-Thornton didn’t disclose her status to many people because she was working in politics and didn’t want it to affect her career. But then she moved back to Chicago, where her health deteriorated over time. It started with yeast infections that she believed were connected to her HIV.

“It was like every time I think I’m on the right path, I get knocked back down,” she says.

She had a booming career working on political campaigns and had served as the national youth director for the Reverend Jesse Jackson’s second presidential campaign in 1988. She had

graduated from college and was earning her master’s degree. She was two classes shy of graduation when life took another turn.

Her HIV had progressed to AIDS, which back then often meant a life expectancy of 18 months. That’s when she started to tell more people about her condition. She felt that she needed to prepare to say goodbye to her loved ones.

“There’s an African proverb that says, ‘He who conceals his disease cannot expect to be cured,’” Lewis-Thornton explains. “I latched onto it. I told friends I was dying so they could prepare for my death. Then came the public speaking.”

Rae Lewis-ThortonKirsten Miccoli

In the early 1990s, Lewis-Thornton started taking azidothymidine (AZT), the first approved HIV drug. She took it as a single therapy for almost three years. But, like many people, she experienced side effects. Lewis-Thornton could barely hold up her body and felt nauseous all the time.

“I started to lose weight,” she says. “I had wasting syndrome really bad. I was tired all the time, but I never stopped taking the medicine because it was the only hope I had for life.”

Then, in 1996, she started taking Norvir (ritonavir), one of a new class of HIV drugs called protease inhibitors that had just become available. She had to take 12 pills twice a day.

The side effects were almost unbearable, but she kept up her regimen because she knew she had to do her part to live as long as she could. Her doctor eventually prescribed Crixivan (saquinavir), another protease inhibitor. She took six pills two times a day and never felt sick.

“I’ve taken just about every class in the first generation of HIV medicines,” she says. “As it stands today, I’ve taken about 20 different HIV meds.”

Even though she also took medication to prevent opportunistic infections, she had three bouts of pneumocystis pneumonia (PCP), a serious infection that affects the lungs.

These experiences taught Lewis-Thornton the importance of early diagnosis and adherence to medication, especially now that HIV treatment is much better. She also explains that she had a great relationship with her doctor, who fought for her when she couldn’t fight for herself.

“I didn’t stop medicine on my own,” Lewis-Thornton says. “I didn’t miss doses. When the medicine had reached a point where I couldn’t tolerate it anymore, [my doctor] would work something else out for me. We were partners in my health care.”

When news of Lewis-Thornton’s condition spread in Chicago, someone reached out to her requesting that she speak at a local school about living with AIDS. That two-day speaking engagement changed her life.

“When I walked into the room [on the second day], it was jam-packed,” she recalls. “Young people were sitting on the floor. Those who had come the day before wanted to come again.”

A young girl in the audience told Lewis-Thornton that God was using her and that she shouldn’t stop speaking. Lewis-Thornton couldn’t shake what the girl said. What’s more, she received many letters of support from other young people. As a result, she quit her job working on a mayoral campaign. She has been sharing her story with the public ever since.

In 1994, Lewis-Thornton made history when she appeared on the December cover of Essence, a national magazine for African Americans. As she says, “It changed the face of AIDS for Black women in America.”

During the early days of the HIV epidemic, women were often overlooked and underrepresented. Lewis-Thornton explains that trying to navigate AIDS as a woman was hard enough. As a Black woman, she also felt especially stigmatized for having HIV.

“The Essence cover was a landmark for Black people,” she says. “It was a culture changer. Women still bring me that article in mint condition and tell me, ‘It changed my life.’”

Lewis-Thornton continued to educate people about HIV as an on-air contributing editor for the local CBS station. In 1995, she reported an eight-part series titled Living with AIDS. It covered topics such as AIDS in the workplace, women with AIDS and the physical effects of AIDS. The series was a huge success and earned Lewis-Thornton an Emmy Award.

“Each night we shared [episodes], I sat anchor,” she recalls. “We had a phone bank. An AIDS organization came in, and we got a ton of phone calls that night. It was like an AIDS hotline.”

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In the early 2000s, Lewis-Thornton earned a master of divinity degree after attending seminary. She was about to start a PhD program, but she kept getting sick. Lewis-Thornton soon learned that she had drug-resistant herpes. She couldn't fight it without IV medication. That meant she was constantly in and out of the hospital.

In 2003, the Food and Drug Administration approved Fuzeon (enfuvirtide), which works against drug-resistant HIV. Lewis-Thornton's doctor prescribed her the injectable medication. She injected it into her belly twice a day.

"It was one of the first in its class, and it was a game changer," she says. "It was also one of the most difficult medications that I've ever had to take. The moment you inject it, a nodule starts to rise. It could be as small as a dime or as big as the bottom of a Coke bottle."

What's worse, she says, is that you couldn't reinject into a nodule. She describes having up to 12 painful nodules on her belly on any given day.

But all those trials and complications got Lewis-Thornton where she is today. Her viral load is undetectable, and her health has, for the most part, been good, she says. As someone aging with the virus, she now worries about the long-term impact of HIV. The drug-resistant herpes still comes and goes. What's more, she has osteoporosis and is currently on medication to treat it because both HIV and its treatment can harm the bones. She's also on medication for high cholesterol, a condition she attributes to HIV meds.

Because of her complex treatment history, Lewis-Thornton isn't on a single-pill regimen. She takes four different HIV medications, for a total of eight pills a day. "I'm trying to figure out how do I live healthy and whole for as long as I got," Lewis-Thornton says. "I never thought I would live to see 60."

But she isn't just thinking about her physical health. Lewis-Thornton has worked to better her mental health for decades. She's been in therapy for 25 years. One of her goals is to unpack and address the trauma she's endured in her life. She also adds that depression affects people living with HIV.

"I don't skip my therapy sessions," she says. "I struggle with depression, and I'm intuitive. I know when I'm about to hit the bottom. So I'll say to my therapist, 'I'm not good right now.'"

Lewis-Thornton especially relied on her therapist and psychiatrist as she wrote her new memoir, Unprotected, which was released in May 2022 and has a foreword by the Emmy-winning actress (and Lewis-Thornton's longtime friend) Sheryl Lee Ralph. The book caused Lewis-Thornton to relive a lot of trauma and triggered her to the point that she had to stop writing for a month.

But she also finds ways besides professional help to ease her mind. She likes crafting, beading and knitting. "I use my hands as my kind of mindfulness work," she says. In fact, Lewis-Thornton

dreams of opening a crafting center for women to give them a safe space to deal with their trauma and anxiety.

“Trauma is important [to deal with], because little girls with low self-esteem grow up to be women with low self-esteem, and that puts us at risk for HIV,” she says. “There’s a lot of soul work that needs to be done.”

She believes that other possibilities must be considered to help the United States get to zero new HIV cases. As she puts it, “Addressing trauma isn’t the whole ball game, but it’s at least a pitch.”

Publishing Unprotected has allowed her to extend a hand to those who may need it most. She hopes to write another book that will show readers how she’s healed from everything she’s been through. But for now, she invites people to see her authenticity and vulnerability in this memoir.

“I show you what trauma looks like and how I survived,” she says. “Surviving is not healing. It’s taken years to deconstruct what people told me I was and who they made me to be to get to the place God created me to be.”

Through it all, Lewis-Thornton has remained a woman of faith. She has always believed that God has a plan for her. She looks back on the moments in her life when God placed what she calls “North Stars” in her circle to give her a “reprieve from the ugly.”

Although she has used her voice to spread HIV awareness within the church, Lewis-Thornton has more work to do within the faith community. She wants to earn a doctorate in ministry and use her book as the foundation for a dissertation focusing on trauma in the church, specifically how Black churches respond to trauma in general and to trauma among Black women churchgoers in particular.

“I’m going to keep using my voice and doing it in my authentic [way],” she says. “I’m still who God ordained me to be in this space, and I’m going to be that person until the day I die.”

Her work to help others will continue. But Lewis-Thornton also has dreams for her own life. She wants to buy a house—one where she can wake up in the morning, step outside with her tea and listen to nature. She wants a place to call her own.

“Beyond that, I just want to live and see what the end is going to be,” Lewis-Thornton says, “because God always has a next, and sometimes the surprises are just mind-blowing.”

Click here to purchase a copy of Unprotected: A Memoir from the POZ Bookstore.

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