



Aging at Home

Longtime HIV advocates share their insights on aging with HIV, including managing overall health.

November 16, 2020 By [Oriol R. Gutierrez Jr.](#)

Sherri Lewis, Derrick Mapp and Jeff Taylor were our guests for the fourth episode of POZ at Home. Titled “HIV and Aging,” the episode premiered on Thursday, September 17, the day before National HIV/AIDS and Aging Awareness Day. POZ at Home is a series of Zoom events that bring together community members to discuss HIV-related topics. As editor-in-chief, I had the pleasure of hosting.

Lewis spent her 20s in New York City as a singer and entertainer. She tested HIV positive in 1987. For more than three decades, she has been an HIV activist. She lives in Los Angeles, where she records music and is writing her memoir.

Mapp is a long-term survivor working as a senior services care navigator and health counselor at the Shanti Project in San Francisco. He is dedicated to volunteering for advocacy efforts for HIV and cancer as well as for the LGBT community.

Taylor is the executive director of the HIV+Aging Research Project—Palm Springs in California, which conducts patient-centered, community-based research on aging and HIV. As a long-term survivor, he has been active in HIV research since the 1980s.

Go to poz.com/athome to watch this episode—which includes a video of Lewis giving a live performance of the Broadway song “Being Alive”—as well as additional POZ at Home episodes. Below is an edited and condensed transcript.

Gutierrez: Sherri, why don’t we start with you.

Lewis: My HIV test came back positive on my 33rd birthday. I was about to get married, was healthy and wanted to get pregnant. I was in Cambridge, Massachusetts, at the time, where my fiancé and his son lived. Of course, all plans were off. My life was radically changed, as it has been for all of us long-term survivors. None of us thought we’d be aging with HIV.

Gutierrez: I tested positive in 1992. I just turned 50 this year, so I really feel like I’m finally part of the aging with HIV club. Derrick, give us some of your story.

Mapp: I was living in New York City at the time of my diagnosis. I remember that even for my doctor, it came as a surprise. I asked him for the test outside of the time we normally would do it because I was having flu-like symptoms. It was a shock to both of us. I still kind of get shaky in the voice about it.

Seeing my response, my doctor immediately connected me to a therapist and got me a taxi. It took me almost a year to get on HIV medication because I couldn't figure out what I wanted to do since it was before effective treatment.

Gutierrez: Let's hear from Jeff.

Taylor: I was in college studying abroad in Japan when I first heard of this thing going around. I returned to Chicago when it was getting scary. When both of the American expats I dated in Japan tested HIV positive, I had a strong suspicion that I was also positive. I didn't get tested at the time because there wasn't much you could do about it.

In 1988, I went for a routine dental exam. The provider excused herself and came back in dressed from head to toe in a biohazard containment suit with a plastic face shield. She said, "Don't be alarmed." It was a little late for that.

She saw oral hairy leukoplakia, which could be indicative of a suppressed immune system. She suggested I get tested for HIV, which came back positive. I was told I had about two years to live, not what you want to hear at 26.

The first thing I did was get a lifetime gym membership to try to prevent wasting away. The second thing I did was enroll in the first clinical trials of AZT, which started me down the research rabbit hole. Knowledge is power.

Gutierrez: Aging with HIV also means we're dealing with comorbidities. Can you all share any related experiences?

Lewis: I didn't take HIV medications for the first 15 years because I believed my T cells were healthy enough.

When I finally started them, I got lipodystrophy. My face caved in, my arms became skinny ballerina arms and my belly became a Buddha belly. The drugs that were meant to prevent AIDS made me look like I was dying from it.

I was cured of hepatitis C, which gives me hope we'll have an HIV cure. I've always been optimistic about staying alive.

Mapp: I've had to deal with my mental health. I'm diagnosed with severe depression, which at certain times can be quite debilitating. The thing that has saved me is talking with people I trust.

Gutierrez: I can relate. Mental health is the most universal thing that we've all had to deal with,

our ups and downs.

So Jeff, please tell us more about the mission of the HIV+Aging Research Project—Palm Springs.

Taylor: Most research has focused on treatment. We also now have biomedical prevention. We're still not doing enough to understand what's happening to most of us living with HIV who are now in our 50s, 60s and older.

Our group mostly looks at psychosocial research. What's it like for people living with HIV to get older? What kind of resiliency do they have? What kind of stigma, loneliness and isolation are they experiencing? These are the things we're focused on right now.

It's also been fascinating to see how folks are doing during the COVID-19 crisis. We surveyed about 100 people over 50 living with HIV to see what their experiences were with the new coronavirus. We were concerned they would go down rapidly with posttraumatic stress disorder and fear, etc.

What we found, and what clinicians are telling us, is that people are really resilient. They've gotten this far because they know what to do. They've been at this pandemic rodeo before.

Gutierrez: Derrick, you're a community representative for the ANCHOR study on anal cancer. Tell us about it.

Mapp: Anal cancer is caused by human papillomavirus (HPV). Changes to the skin around and inside the anus can result from HPV. These changes are called high-grade squamous intraepithelial lesions (HSIL). About half of men who have sex with men living with HIV have anal HSIL. Most HSIL resolve on their own, but some could turn into cancer. To prevent anal cancer, would it be better to just observe HSIL as they develop? Or is it better to actively treat them? Those are the central questions.

Gutierrez: Part of aging with HIV is about remembering those we've lost, but also celebrating those who remain. To that end, STORIES: The AIDS Monument is currently under construction in West Hollywood, California. Sherri, you're on the board. Please tell us more.

Lewis: In terms of stories, it's not just restricted to West Hollywood. We're working with @TheAIDSMemorial on Instagram to share stories from everywhere. It's not a building, but instead, it's a beautiful outdoor structure.

It's going to be gorgeous. And it's very emotional. Sorting through the stories was a part of my committee. I want to continue focusing on the stories of women and children that were so badly overlooked in the past.

Gutierrez: A question from the audience: Derrick, would you consider being Black in America a comorbidity?

Mapp: Absolutely. In fact, I see what's happening today as a pandemic of a lack of empathy. That's in terms of all health inequalities for COVID-19 and HIV.

Gutierrez: Another audience question: How do we help younger folks understand what we've gone through?

Lewis: It's a challenge. I used to visit schools all the time to share my HIV story. We need to keep going to schools; we still need to write and speak about all the things that we've gone through. Whether it's high schools or colleges, HIV isn't really part of the curriculum.

Gutierrez: Thank you all for sharing your perspectives on aging with HIV.

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