Aging With HIV: Living to Tell

Long-term survivors aging with HIV are full of resilience that comes with learning how to cope, connect and dream again.

October 1, 2019 By Tim Murphy

In early August 2019, Pat Kelly, of Orangeburg, South Carolina, was busy packing for a big trip to Vegas. It would entail shopping, a visit to the Hoover Dam and a night out to see the comedian Eddie Griffin. She would be one of a group of friends—all women living with HIV—making the trip, and, most important, it would mark her 65th birthday.

“I never thought I would make it this far,” she said. “That’s why I’m celebrating royally.”

Tested for HIV without her consent and diagnosed positive in 1985 while serving one of several drug-related prison sentences, Kelly has now been out of prison and drug-free for two decades and has lived with the virus for nearly 35 years. That makes her one of the roughly 50,000 Americans commonly referred to as long-term survivors of HIV.

These folks were diagnosed with HIV before 1996, the year that effective treatment emerged. Some of them were diagnosed (based on such metrics as low CD4 counts) even before the actual HIV test became available in 1985.

That means such individuals often went many years without effective HIV treatment—not to mention they lived with the ever-present fear that they might die within months. No wonder, then, that many of them—like Kelly—consider it a near-miracle that they’re still alive.

Today, 47% of all Americans living with HIV are over 50; by 2030, it’s estimated that figure will be 70%.

“I’m still here,” declares Kelly, the founder of A Family Affair, a South Carolina–based group that provides support and knitting circles for women living with HIV and their family members. “I’m surviving and thriving, the grandmother of eight and great-grandmother of seven. I didn’t think I would live to be an elder, but I am!”

That’s not to say the road to elderhood has been easy for Kelly—or for most long-term survivors. Many of them already identified as gay, people of color, people who use drugs, transgender or some combination thereof before they were diagnosed, meaning that being HIV positive in the 1980s and ’90s only added to the stress, stigma and discrimination they might have already been

experiencing.

Back then, knowing that one might die at any time as a result of an untreatable virus often contributed to years of depression and anxiety that sometimes manifested in escapist drinking or drug use, a tendency to isolate or an understandable indifference to one's well-being.

Further complicating matters was the sudden realization, circa 1996, that one might live a long life—with all its accompanying bills, career challenges and other hassles—after all. That's a lot of emotional whiplash, especially after, in many cases, having buried many friends and lovers lost to the virus along the way.

Fast-forward to today, when it often seems that the culture has moved on and that—between pre-exposure prophylaxis (PrEP) to prevent HIV and effective treatment to keep people diagnosed with HIV healthy and unable to transmit the virus sexually—the virus just isn't a big deal anymore.

"We long-term survivors are facing invisibility," says Tez Anderson, 60, who was diagnosed with HIV in 1986. He's the founder of the support group Let's Kick ASS (AIDS Survivor Syndrome). Started in San Francisco, where Anderson is based, the group now has chapters in other cities, including Palm Springs, a mecca for long-term survivors in the middle of the California desert.

"We're living in an age where we're taking on ending the epidemic and creating an AIDS-free generation, and most survivors I talk to feel like we're forgotten, relics of a bygone era who have no right to complain because now we've got good medications," he says. But that attitude, he notes, denies the trauma that comes with having lived for years in a state of fear, uncertainty and depression.

Of course, the flip side to the challenges of being a long-term survivor is the tremendous coping skills that many have developed over the years. "We came together heroically as activists and found strength we didn't know we had," notes Anderson.

"For many years, I focused only on how many times I was sick or how many people I had lost, and I wasn't focusing on the fact that I always got up," he says. "Then I started thinking, 'Hmm, maybe I'm resilient.' And then that changed to 'I am resilient.'"

Indeed, the landmark 2006 Research on Older Adults with HIV (ROAH) study, conducted by the ACRIA Center on HIV and Aging at GMHC in New York, found significant levels of depression, posttraumatic stress disorder (PTSD) and social isolation among its nearly 1,000 participants in New York.

But, according to ROAH researcher Mark Brennan-Ing, PhD, both ROAH and its follow-up, a study of a smaller group of older San Franciscans living with HIV, found high levels of resilience, an ability acquired over decades of adversity to roll with the punches and make the best of things via community building.

"I walked into a focus group of older HIV-positive transgender folks the day after Trump was

elected," Brennan-Ing recalls. "They were scared, but many said, 'We've been through so much worse—we're going to get through this.' They recognized the need to be there for one another and as a community."

Aging is hard enough, but aging with longtime HIV can present special challenges. Folks with HIV have now lived long enough for researchers to observe that they tend to experience age-related health problems—such as bone weakening, muscle loss, cardiovascular disease and a host of cancers—a decade or more earlier than HIV-negative people, even if they are on HIV meds and have an undetectable viral load. In part, this is likely related to inflammation, the overactivation of the immune system as it constantly wages a battle against HIV.

"It's also called 'inflammaging,'" says Brennan-Ing. Nonetheless, he notes, "we still don't have a great understanding of how HIV affects the aging body. People aging with HIV tend to blame everything [going wrong physically] on the HIV, whereas in fact the jury's still out on that."

One thing is certain: As with HIV-negative people, six factors that play the biggest role in the health and longevity of folks with HIV are exercise, a healthy diet, not smoking, minimal alcohol intake, staying in regular medical care and social and emotional support. So it's wiser to focus on what can be controlled than on what cannot.

The importance of quitting smoking cannot be overstated. HIV aside, it's the single greatest factor in reducing or avoiding a variety of bad health outcomes, including heart disease and many kinds of cancer.

For Enrique Menendez, 54, a New York–based entertainer and casting director diagnosed with HIV in 1989, a major part of his acceptance that he was going to live longer than he thought was kicking the butts—in his case, with the help of a smoking-cessation drug. "I've had one cigarette in the last three months," he says, "and I'm OK with that. I never planned for a future, and now I'm having one, so it's kind of weird to me."

Beyond that, regular exercise (especially including some form of weights or resistance training) and a diet rich in fruits, vegetables, whole grains and lean protein (chicken, turkey and fish) and sparing in sugar, white flour and processed and fried foods are all essential. Menendez says he hits the gym three to five days a week, plays softball in a gay league and maximizes his intake of produce while minimizing white bread, rice and pasta.

For San Francisco's Patti Radigan, 62, a part-time accounts payable manager diagnosed with HIV in 1992, her physical and mental health savior over the past 20 years has been yoga. Not just practicing it but also teaching it once weekly to other Bay Area HIV long-term survivors via Anderson's Let's Kick ASS network.

"I was so depressed, all by myself, and had toyed with the idea of suicide," she says. "Then I went to Let's Kick ASS and found there's a community of people who felt the same way." Her yoga classes began shortly after that. "It's given me a purpose," she says.

Long-term survivors often talk about the existential challenge of figuring out what to do with the rest of their lives once they realized they likely weren't going to die anytime soon. For Billie Cooper, 61, a transgender San Franciscan diagnosed with AIDS in 1983, for many years, the answer came in the form of drugs.

"They helped me forget about the HIV, about my fear and stigma over my status," she says. But eventually, she continues, "I got tired of having nothing—not having a life, not being a human, people calling me a drug addict and avoiding me, not taking care of myself."

One morning in the early 2000s while in her room in a single-room occupancy building in the Tenderloin District, she decided she'd had enough and checked herself into Walden House, a residential treatment center. There, she says, "I found my purpose: to be a productive human being, a Black trans woman whom people don't look down on. I realized I had a voice and could make a difference."

At San Francisco AIDS Foundation, Cooper started TransLife, a support group for trans women. Now, she says, she derives strength and joy from "waking up in the morning and going to sleep at night knowing that if a trans woman needs help, she can come to me. I'm finally giving back."

Tez AndersonCourtesy of Tez Anderson

Before he started Let’s Kick ASS, Anderson, too, experienced the same crippling depression Radigan and Cooper describe. “I was angry, depressed and couldn’t sleep,” he says. “I wasn’t even doing drugs or drinking. Then I saw a TV show on PTSD and realized that I was dealing with

trauma. I started looking into it, but I could find nothing about the trauma of surviving HIV for so long. So I coined the phrase 'AIDS Survivor Syndrome,' and talking to other long-term survivors, to a person, they had the same feelings as me."

This all led to a town hall in San Francisco in September 2013 that launched Let's Kick ASS and kick-started HIV Long-Term Survivors Awareness Day, observed every year on June 5. This awareness day follows in the footsteps of National HIV/AIDS and Aging Awareness Day, which was started in 2008 and is marked each year on September 18.

"I thought maybe 40 people would show up, and we had 250," Anderson recalls. The group now has 2,700 members worldwide on its Facebook page and holds events all over the United States, Canada and Europe. Anderson says he wants to organize a conference in 2021.

Of course, finding meaning and connection can be tough when you're also worried about aging in poverty, a common anxiety among long-term survivors, who often went on disability and lost valuable income for several years.

"Many of us didn't plan financially," says Vince Crisostomo, 58, diagnosed with HIV in 1989, who now runs the San Francisco AIDS Foundation's Elizabeth Taylor 50-Plus Network, which encompasses a wide variety of weekly or monthly support groups, social meet-ups and volunteer opportunities.

Crisostomo himself, who has long worked in HIV/AIDS services, says he took the job "because it was that or food stamps," but he has since come to love how his community of hundreds of long-term survivors share their strength, wisdom and joy with one another. "A lot of healing has gone on," he says.

Of course, options for health care, housing, food, transportation access and other resources, both financial and emotional, vary wildly by city or state, but Crisostomo urges long-term survivors, wherever they are, to contact their local HIV/AIDS group or other area nonprofits or public agencies.

People can reach out to find someone to sit down with and work out a practical life plan for the years going forward, one that may include some combination of available public benefits and/or part- or full-time work. "Some people move to Palm Springs, but many move back to their hometowns to be closer to family," he says.

He also acknowledges that it's generally easier for long-term survivors to find connection and community in cities with large populations of them, such as New York, San Francisco, Palm Springs and Fort Lauderdale.

Long-term survivors in smaller cities or fairly isolated rural areas may have to look harder for even a handful of friendships with others who understand and, ideally, share their survival stories.

But Crisostomo urges folks to make the calls or the internet/social media connections necessary to

forge such a support network. “You can become very comfortable living in isolation,” he says, “so try to move past your comfort level.”

That’s exactly what Pat Kelly did when she started A Family Affair (AFA) to bring together all the long-term survivor women in her region for mutual support, comfort and fun.

“I just ran into a girl who was part of AFA many years ago when she was struggling with her baby, and now her son is 16 years old,” Kelly says. “She came up and hugged on me!” The moment reminded her, she says, that “we’re here for a purpose. We’ve survived so much against the odds. We all have a destiny and a purpose.”

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