Stand By Me

For long-term survivors, the key to embracing resilience is sticking together.

May 18, 2020 By Tim Murphy

Now 64, Ed Barron tested HIV positive in the mid-1980s. Jumping around in time, he tells POZ his life story in a raspy tough-guy voice that often quickens and intensifies when he gets emotional. It's a remarkable, sweeping tale of how someone who was completely lost finally found himself.

From the hedonistic gay bars and clubs of Manhattan in the '70s to the AIDS hospital wards and spiritual support settings of the '80s and '90s to the post-protease meth dens and rehabs of the 2000s through the HIV activist rallies, protests and conferences of the 2010s, the arc of Barron's life story is familiar to many long-term survivors.

He found himself by connecting to a broader world of long-term survivors, all of them rallying to fight not only for their own lives but also for other health- and poverty-challenged people.

The change for Barron, who lives in New Jersey about an hour outside Manhattan, started around 2010 when, long battered by AIDS, hepatitis C, cancer and addiction, he went on a spiritual retreat for men called Body Electric.

"At the climax," he recalls, "I'm blindfolded and curled up nude in a fetal position, wrapped in a blanket, thinking about being abused as a child, crying. Then I start to warm up, and I start laughing, and I think, 'I'm one strong motherfucker!'—if you'll pardon my French. 'I survived!'"

Soon after that cathartic experience, Barron saw United in Anger, the 2012 documentary about the early days of the AIDS activist collective ACT UP. Later, he went to his first meeting of the current ACT UP New York group, whose small cadre was, until recently, still meeting weekly. (At press time, the new coronavirus disease known as COVID-19 had put a hold on large gatherings.) "I thought of how self-centered I'd been, using drugs all those years that people were out there fighting so I could live," Barron says.

With that realization, he threw himself into activism, becoming a veritable midlife warrior. In addition to attending local ACT UP meetings, he traveled to AIDSWatch, the annual Washington, DC, lobbying summit for people with HIV/AIDS, and he joined the New Jersey HIV Planning Council and the state's major HIV/AIDS agency, Hyacinth.

On June 5, Barron will participate in New Jersey's inaugural celebration of the annual HIV Long-

Term Survivors Awareness Day, telling his story of HIV, addiction and recovery on a panel with other survivors, including cisgender and transgender women.

He also works part-time at a garden center, despite being partly confined to a wheelchair. “My boss says to me, ‘I don’t know how you come in here so happy every day with everything you’ve been through,’” Barron says. “And I say, ‘I could sit home and feel sorry for myself, but I’m alive, and a lot of my friends are not.’”

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Who qualifies as a long-term survivor is in the eye of the beholder. However, the term is most commonly used to describe a core group of individuals who’ve lived with HIV since before 1996, the year effective treatment became available. That said, it can also apply to the more recently diagnosed or to HIV-negative people who also lived through the darkest times, nursing and losing friends and lovers.

Definitions aside, how do we understand what separates the Ed Barrons of the world, who find a reason to live despite crushing losses, from folks like Dave Mills?

Earlier this year, Mills, a long-term survivor living in Florida, sent a suicide letter to fellow long-term survivor Tez Anderson of San Francisco. Alongside a few others, like New York City’s Sean McKenna, Chicago’s Jeff Berry and Berkeley, California’s Matt Sharp, Anderson has taken on the challenge of connecting the roughly 50,000 Americans who’ve lived with HIV since the pre-protease days. He is also the founder of HIV Long-Term Survivors Awareness Day, observed every June 5.

The letter read: “Tez, unfortunately, if you are reading this, it was mailed when I’d reached a point where suicide was the only option left to me…. I became too tired fighting to preserve my dignity and quality of life, to fight any more just for the sake of survival.”

By the time Anderson received the letter, Mills had indeed taken his own life.

Anderson posted the news on his Facebook page, Let’s Kick ASS—AIDS Survivor Syndrome, which has thousands of followers. “He was 65,” wrote Anderson. “He mentions AIDS Survivor Syndrome, PTSD [posttraumatic stress disorder], poverty and a lack of services as factors in his decision to end his life…. It was a crisis of belonging and despair.”

Tez AndersonJeff Singer

On Anderson’s page, reaction to news of Mills’s suicide was intense. Wrote one person: “It’s so sad that we live in a world of indifference where poverty, alienation and HIV phobia still surround long-term survivors.” And another wrote: “I am one paycheck from being homeless, and I know the struggles that he went through.”

Anderson says long-term survivors feel left behind by AIDS service organizations, which have increasingly focused their efforts on HIV prevention. This includes both pre-exposure prophylaxis (PrEP) and the Undetectable Equals Untransmittable (U=U) message, which promotes the fact that people with HIV who maintain an undetectable viral load cannot transmit the virus via sex, even without condoms. Together, PrEP and U=U are the golden keys to campaigns to end the epidemic, the current focus of health agencies nationwide, from the Centers for Disease Control and Prevention on down.

“I saw a draft of California’s new Ending the Epidemic plan,” he says. “There was not much in it about aging.” Anderson, who has lived with HIV since the 1980s, insists that long-term survivors have a role to play. “We’re the elders, and we know a lot about life and death. We need to be included—not left to live in isolation.”

The many physical deficits that come with living for decades with HIV have been well documented—the chronic inflammation that accelerates aging of the bones and the brain and other organs and the cascade of medication side effects, including neuropathy, lipodystrophy and more. However, it does seem as though at the heart of AIDS Survivor Syndrome are the profound depression and isolation that come not only from having survived the loss of so many loved ones, but also from living, almost ghostlike, in a world that has marched on.

To Anderson, whose Let’s Kick ASS page has spawned support groups in cities nationwide, that kind of isolation has only one palliative, if not a cure: “It’s about finding others who understand and putting them together,” he says.

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Fortunately, groups across the country are helping long-term survivors find solace in one another.

In Baltimore, Older Women Embracing Life (OWEL) has been meeting for 17 years. “About 15 to 20 of us women show up once a month,” says founding member Stephanie Brooks-Wiggins, 74. “We have a yearly conference that draws hundreds of women from all over the Eastern seaboard. We share info, we have guest speakers, we have lunch and we share our feelings, what we’re going through. Women are still hiding their diagnoses from family and friends, so we give them an outlet to share that with women in the same boat.”

Melanie Reese, 68, who became OWEL’s executive director when its beloved former executive director Carolyn Massey died two years ago, says: “The first time I went to the group in 2005, my jaw dropped to see other women who looked like me going through the same ups and downs of living with HIV. It was OK there to just listen, to hug someone without fear of them rejecting you, to share our good and not-so-good experiences, to pray. I felt so supported and so loved.”

In Chicago, the aforementioned Berry and Sharp started The Reunion Project five years ago. They have hosted a series of town halls, not just in Chicago but in other cities, including Philadelphia and Atlanta, for long-term survivors—both positive and negative—to come together.

Attendees of a 2018 event hosted by The Reunion ProjectCourtesy of The Reunion Project

“All these issues of PTSD, trauma and isolation were coming up, and, just like the Holocaust or the Vietnam War, people needed several years to pass before they could revisit what had happened,” Berry says. “We tell people that it’s not about how long or whether they’ve been living with HIV but if they personally identify as a survivor, which includes allies, such as relatives, friends and nurses.”

At the town hall in Philadelphia, Berry says, he met a long-term survivor living in isolation 45 minutes outside the city. “She told me she’d never publicly discussed having HIV and halfway to the town hall she was so scared that she’d almost turned around and driven home, but that she decided to stay and was so glad she had.” Berry also regularly hears from people who say they suffered years of alcohol and drug abuse before going into recovery and only then becoming ready to discuss the plague years.

“It can get really deep,” he says of the town halls, “but we try to keep it going.”

In Chicago, there’s also a small Let’s Kick ASS group of both positive and negative older men (though they’re open to all genders) who meet weekly. The group is led by Joe Knell, 60, who is HIV negative. He says he didn’t even know that AIDS Survivor Syndrome was “a thing” until he discovered Anderson’s Let’s Kick ASS page.

“I lost friends who were very important to me,” Knell says. “For years, I’d experienced depression,

anxiety, always being on edge and angry, hypervigilant. When I read about those symptoms, I thought, 'I've had these.' Then I thought that there had to be other people in Chicago who've experienced these symptoms." Hence, he started the group.

"Jim," who is living with HIV, is a fellow member. "I've had problems with depression and anxiety for years, and I realized that a lot of it started when the epidemic took off back in the 1980s," he says. "I didn't know what to expect when I first came to the group, but the meetings made me realize I wasn't the only one around who has been affected—and that's a good feeling. I feel really close with the people here and look forward to talking with them every week."

In New Jersey, married mom Xio Mora-Lopez, diagnosed with HIV in 1994, discussed how for years she lived in near-total secrecy about the virus. "I had never met other people living with HIV or been to a support group," she says. "I had severely isolated myself." Then in 2016, at a breaking point, she participated in a World AIDS Day open mic event for HIV long-term survivors at New York City's Judson Church and told her story publicly for the first time. "I felt empowered and free after that," she says, "supported by a community."

She now regularly attends GMHC's 50 and Beyond group for older folks with HIV. "It has absolutely changed my life for the better," she says—and that's despite living with side effects of long-term HIV and its treatment, such as gastrointestinal issues and severe neuropathy in her hands. "I needed to find people I had something in common with and go from there," she says.

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To be clear, joining a group of fellow long-term survivors is definitely not a silver bullet. Brooks-Wiggins, who acknowledges deriving huge support and joy from OWEL in Baltimore, says, "Mind you, I still get depressed. I've been treated for depression, and I've seen both a therapist and a couples counselor."

However, as many long-term survivors put it, having a support circle of any sort—which can also include non-HIV-related family and friends—can take the edge off depression, anxiety and isolation. San Francisco's Hank Trout, 67, diagnosed with HIV in 1989, puts it very simply. He says that since he started attending San Francisco AIDS Foundation's Elizabeth Taylor 50-Plus Network, "I don't feel so alone anymore. Prior to that, everyone I had known was dead, and it didn't occur to me that there were other survivors out there."

Obviously, not everyone lives in major urban areas that lend themselves to getting together. Although fellowship is vastly harder to find in rural areas, it can be done.

Edwin Brandon, 60, was diagnosed in 1983 with GRID (gay-related immunodeficiency), which eventually came to be known as AIDS. Nine years ago, he left Memphis, where he had been well connected in HIV circles, for rural Tennessee to care for his aging parents. Nonetheless, he still goes to Jackson, Tennessee, once a month to sit on his region's Ryan White Planning Council; the rest of the time, he stays connected online via groups like Let's Kick ASS. For folks like him who

are physically isolated, “you have to forge ahead and invest some time in finding a group online that meets your needs,” he says.

Recently, Brandon adds, he participated in an online smoking cessation group for people with HIV. It helped him kick the habit after 40 years, but once he left the group, he says, “I felt like I was losing friends. You can grow to care about people, even virtually.”

Mora-Lopez agrees: “Real-life contact with people is a deeper connection, but that online element can be a lifesaver.” This is especially true now during the COVID-19 crisis.

Everyone’s different, of course. In his suicide letter, Mills complained of a lack of support from his local HIV agency, but in fact, he had struggled with depression since well before his HIV diagnosis, and it’s possible that all the support in the world might not have saved him. We’ll never know.

For long-term survivors struggling to get by today, “I’d encourage them to keep trying to find a venue—physical or online—where they feel safe enough to talk,” says Baltimore’s Brooks-Wiggins. “You’re not going to open up until you find that.”

Thankfully, New Jersey’s Barron did. “I was disconnected for so many years,” he says. “The person I am today is not the person I was 10 years ago. I realize that I’m alive while a lot of my friends aren’t. While I’m still around, I’m going to have a purpose.”

Looking for Connection?

- Go to Let’s Kick ASS on Facebook to find a group—or at least other long-term survivors—near you. Consider joining the online conversation.
- Call your local HIV agency to join—or maybe start—a group.
- Visit The Reunion Project, the Shanti Project of San Francisco and OWEL online.

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