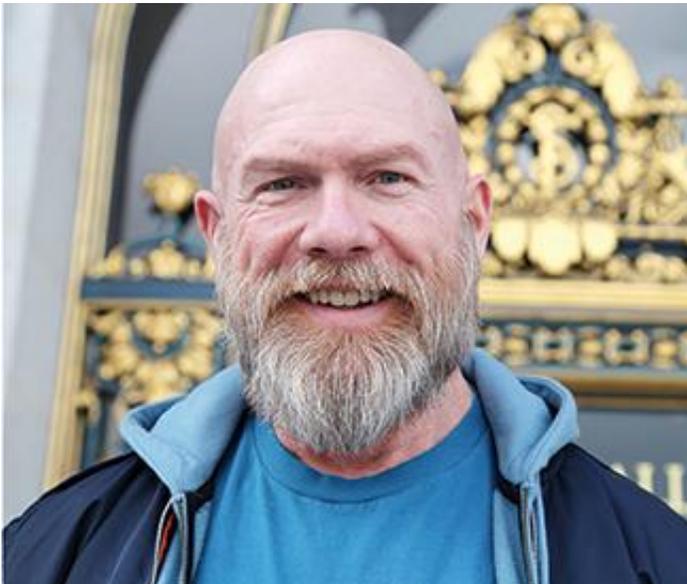


Staying alive

By *Kate Conger*

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Support group addresses AIDS Survivors Syndrome and the challenges of cheating death



Tez Anderson is a longtime AIDS survivor who cofounded Let's Kick ASS.

GUARDIAN PHOTO BY JUAN PARDO

By all accounts, Tez Anderson shouldn't be alive today. When he contracted HIV in 1981, doctors gave him only two years to live. Somehow, he managed to outlast that prognosis by three decades.

"People ask me how I'm still here, and honestly, I don't know," he told the Guardian during an interview in his small office above Harvey's Restaurant in the Castro. "I would get these little reprieves — two more years here and there — and I just got used to living like that."

Muscular and energetic, Anderson has a surprisingly light-hearted demeanor for someone who has lived with death for his entire adult life, but there's no denying that he has been through a severe and sustained trauma.

By 1992, AIDS had killed more residents of San Francisco than all four major wars of the 20th century combined. As a result, Anderson watched an entire generation of his friends — people whom he cared for and loved — succumb to the virus.

The loss has taken its toll. For years, Anderson suffered from severe anxiety, deep depression, and rage. At times he even considered suicide. While driving the windy hills of San Francisco, Anderson would occasionally imagine letting go of his steering wheel, sending his car careening down the hill.

"I was planning it out so that it would look like an accident," he said. "I didn't want people to be hurt by the fact that I killed myself."

Like Anderson, many AIDS survivors suffer emotional ailments akin to post-traumatic stress disorder or survivor's guilt. Walt Odets, a Berkeley-based psychologist who has worked with hundreds of gay men who lived through the AIDS epidemic, is convinced that a mental health crisis is unfolding among long-term HIV survivors.

"There's an inability to live with vitality, to live with richness, to get up in the morning and feel like you have a future, if only for the day," he told us. "We're losing a lot of vital lives over this."

Anderson believes that many AIDS survivors have a definable psychological syndrome. Last January he decided to give it a name: AIDS Survivor Syndrome, or ASS for short (the acronym was intentional). He and two friends, Michael Siever and Matt Sharp, have since formed the group Let's Kick ASS.

Every Tuesday, they host a meditation class, and on Saturdays they convene at the Church Street Café for coffee and conversation. On the third Wednesday of each month, the group puts on large workshops and forums.

Just like during the 1980s and 1990s, when HIV-positive people built a social movement around AIDS, Let's Kick ASS is trying to unite the community in the face of hardship.

"There's nothing that will take away or fully heal this wound," said Gregg Cassin, who has had HIV since the 1980s and works closely with Let's Kick ASS. "But as we learned from the early days of the epidemic, coming together as a community is where the healing takes place."

COMING TOGETHER

On a warm evening last September, Anderson hustled to set up tables and chairs in a large event space at the LGBT center on the outskirts of the Castro. It was the first town hall meeting for Let's Kick ASS, and he had no idea what to expect. At most, he thought that 50 people would show up.

At around 6:30pm the first guests started to arrive. Then a few more people trickled into the room. By 7pm, every seat in the house was taken, and people were wedging into any available nook and cranny. Some of the attendees hadn't seen each other in years and were hugging each other.

"I was blown away by how many people wanted to hear about the group," Anderson recalled. "It felt like a class reunion."

In the end about 200 people — almost all HIV-positive men over the age of 50 — came to the

town hall. People shared stories from the past and discussed how to support each other in the future. Siever noted that many of those who came to the meeting had lost touch with the broader gay community.

"We opened up a space for them to come together that needed to be opened up, but wasn't there anymore," he said. "It was, and still is, amazing."

It may seem odd that only now, more than 30 years after the Center for Disease Control first reported HIV in the United States, survivors are showing symptoms of severe emotional trauma. But such a delay isn't uncommon; it wasn't, for example, until the mid-1960s that psychologists first noticed "survivor guilt" among those who lived through the Holocaust.

"Many people believe that after a huge disaster, whether it's AIDS or something else, it takes about two decades for people to finally get to a place where they're ready to process and heal," said Robert Grant, who has studied AIDS since 1982 and is now a researcher at UCSF's Gladstone Institute. "People are just now starting to figure out what happened to them."

Processing such a massive loss can cause a host of psychological ailments. Last year the San Francisco AIDS Foundation started a group for aging gay men called the 50-Plus Network. When asked what their "biggest issue" was, an overwhelming majority of the participants said social isolation.

"If you have strong connections with people and they keep dying, pretty soon you pull back," said Jeff Liephart, senior director of programs and services at the SF AIDS Foundation. "The unconscious sense is, 'if I create a new relationship, they're just going to die too!'"

Along with feelings of isolation, Liephart said many AIDS survivors are bewildered by the fact that they survived the epidemic. Being HIV-positive during the crisis years was like knowing you had a time bomb inside of you that could go off at any moment.

"If you're in a life-threatening situation like that you can't process stuff," he explained. "Your brain just won't let you do it."

STILL HERE

Anderson has spent over three decades fighting HIV. In 1993 — just prior to being diagnosed with AIDS — he had his first opportunistic infection and came down with pneumocystis pneumonia. Several years later his T-cell count dropped to 12, a dangerously low level. Today, Anderson suffers from severe neuropathy in his hands and feet and is technically disabled.

Still, he has the virus more-or-less under control, and in 2005 he decided that AIDS wasn't going to kill him in the immediate future. This seemingly positive insight triggered a full-blown psychological crisis.

While working on a movie production with an ex-boyfriend (Anderson co-wrote the screenplay for the 2006 movie *The Night Listener* starring Robin Williams) he became noticeably agitated and was quick to get into verbal altercations. Within a year he had pushed away most of his

friends.

Anderson partially attributes his self-destructive behavior to the realization that he might live into old age, a thought he never considered during his entire adult life.

"I spent so many years planning my own funeral, preparing everyone around me for my death, and I never planned for my future," he explained. "Being so intimate with death does something to your head. It makes you unable to make long term plans."

Only now, at age 53, is Anderson getting ready to live a full life. When asked about retirement, he let out a chuckle. He has no 401(K), Roth IRA, or contingency plan. Many of his HIV-positive friends over 50 are in a similar predicament, but he's optimistic that if they come together, they'll be able to figure out a solution.

Over half of the people with AIDS in San Francisco are older than 50. As a result, AIDS service providers in the city have started paying much more attention to the mental and physical health ailments unique to long-term survivors. In 2012 UCSF started the Silver Project, which offers medical and social services to older people with HIV. The AIDS Foundation runs the 50-Plus Network, and the Alliance Health Project has been running a support group for gay men over 50 for the past five years.

These organizations all do similar work to Let's Kick ASS, but Anderson believes his group is different in one fundamental way: It's a nonhierarchical grassroots effort focused on peer-to-peer support. This philosophy was apparent at a recent Let's Kick ASS town hall meeting, where a group of about two dozen men — mostly older, gay, and white — sat in a circle and shared why they had come to the event.

"I've put all of my experiences into a box, and I'm here to open up that box," one man said. "I'm here to find my community again," another added. Anderson was quiet throughout most of the meeting, but he chimed in a few times. At one point, he reminded everyone in the room that the space belonged to them.

"We have 20 years until the real curtains fall," he said, "and we have a chance to make those next 20 years amazing."

After Anderson made his comments, he sat down, crossed his arms, and listened closely as the group continued sharing its stories. The man, who had recently contemplated suicide, now has a new appetite for life.

"I read Joseph Campbell a while ago, and I remember him saying, 'follow your bliss', find that thing that you're passionate about and do it whatever it takes," he said. "I've found my passion, and now I'm not angry, I'm not depressed, I'm not anxious, I have a happy home life. I've found my passion, and I have a community again."

LetsKickASS.org
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