

coming of age amid grief, death and aids

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THERE ARE CHOICES one makes in life, and then there are experiences one doesn't so much choose as simply have. I became a member of ACT UP New York in 1988, when I was 17 years old, because I lived in a part of the world—gay Greenwich Village in the mid-to-late 1980s—that was a kind of ground zero for the AIDS epidemic in the US. Today, I live in straight and straight-laced Washington, D.C., where I work as a political journalist, and am as distant from the ongoing struggle for an AIDS vaccine and better treatments as the average member of the American public, though somewhat better informed about the history of these efforts.

I cannot claim that my own experiences represent anything in particular—in fact, I am certain that they don't—but in retrospect, my youth at the time I was involved with ACT UP was unusual. And in my memory of those years, perhaps, can be found some insight into how a person who knows little about life confronts a world that seems only full of death.

As AIDS continues to devastate nations around the world, millions of young people struggle in far different circumstances with a similar conundrum: How to live and build a life when

the world around you seems to have been upended before you arrived in it. More than a dozen years after I left ACT UP in 1991, the memories of those early years and battles remain strong. But the only take-home lesson I can offer should come as no surprise: AIDS messes with young people's heads.

What I remember most about those years was not the anger that fueled our work, or the camaraderie that gave us strength, or the hours upon hours of work we did—staying up all night writing reports and painting signs and banners and emerging into the early New York morning feeling virtuous and purposeful. What I remember most is the grief. “We are all people living with AIDS,” went one of the slogans of the day. And it was true. In gay communities where 40 to 50 percent of men were infected, people lived with loss as a constant background presence, a grief so shared as to seem somehow unworthy of acknowledgement, and yet deeply affecting each of us.

Larry Kramer asked people to live each day as if they might die tomorrow. It was a powerful rhetorical exercise for conveying the sense of urgency he had about the epidemic. And for many who were HIV-infected in that early medical era—when AZT was the only approved medication and there were not yet any particularly good treatments for opportunistic infections—it was not too far removed from being a realistic worry. But it was also not a particularly good framework for thinking about life as a young person. The natural trajectories of social development got broken and contorted by AIDS. I was moving into the world while too many people I knew were moving out of it—including many not much older than myself.

I recall Phil Zwickler telling me, when he was diagnosed with CMV and going blind, as if he'd just realized another thing he was going to miss by dying young: “I'll never get to see another Democratic president.” George H.W. Bush was still in office, and before that we'd had only the Carter interlude to break up the Republican grip on the presidency that stretched from 1968 to 1992.

I recall Jerry Jontz in the hospital in the awful summer of 1991, the streets of New York so hot you could smell the *E. coli* in the gutters, the sidewalks full of girls in mini-skirts

and platform sandals. Myself, still not college-educated and so broke I subsisted on 35-cent cheese sandwiches from a Puerto Rican bakery. The city was in the grip of the Bush recession, full of “Going out of Business” signs in storefronts and the sounds of Naughty by Nature blasting out of car windows. By August, the whole city seemed to have reached some desperate, sweltering pitch. And Jerry lay dying in St. Vincent’s Hospital. In 2001, that facility became the designated center for trauma victims on September 11, then spent weeks shrouded by a thin blanket of “Missing” posters, one decade’s tragedy overwriting another’s. AIDS had decimated far more of that hospital’s community in the 80’s and 90’s, but no nations then rallied to show their support. What we went through in New York in those years we went through alone.

One day Jerry could no longer recognize me. He could no longer see properly, or speak. He’d reach for an imaginary something just above and in front of his face. Swelling of the brain, the doctors said. Then came a short series of days when he did nothing but moan.

Sometimes the group held open casket funerals. Jon Greenberg wanted a political funeral; I said good-bye by bending over to touch his still, cold arm in Thompkins Square Park. By making the grieving public, a spectacle, his friends tried to include the world in their sorrows, and demand that its members involve themselves in the project of helping do something to alleviate them. I was 19 that year.

When I finally went to college at age 21, I met 19 year-olds who might as well have been raised on a different planet. I tried joining one of the college AIDS counseling groups, for continuity’s sake, but gave it up after I found myself having difficulty taking the worries of my sheltered fellow students seriously. Their troubles seemed so minor. Nor did the world I’d seen do anything but frighten them. I learned not to talk about the past.

AIDS is no longer a part of the world I experience. It seems strange that this is possible, but in the US, AIDS is so concentrated in certain communities that if you leave those

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circles you can go years without ever coming across more than a few people who are infected. And the advent of combination therapies in the late 1990's really did change AIDS from a death sentence into a chronic, largely manageable—though still incredibly difficult—medical condition for many in the world's wealthy countries. Even many infected individuals who once lived as if they might die tomorrow began thinking about how to live again—I mean really live, and not just survive.

My introductory experiences with the world are not something I would wish on another generation. And yet, they are decades—and a vaccine—away from being the kind of thing no one will ever know again.