# Surviving Life Itself

An essay on relevance as a long-term survivor in the here and now.

May 8, 2015 By Mark S. King

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The young woman sitting across from me on the bus is in her mid-20s. She turns to her companion and her voice grows serious.

“I know someone who died,” she says in the hushed tone reserved for tales of mortality. Her friend looks up from his phone. “He was a good friend of my brother,” she goes on. “He was killed in a motorcycle accident a few months ago. It was just awful.” As her friend offers words of comfort, my own thoughts produce a rueful smile and a nagging question.

Just one? You know just one person who died?

By the time I was her age, death in my social circle was so commonplace the body count approached the toll of a commercial airline tragedy.

I listen as the woman reverently shares the details of the accident, of the shock waves that surged through the family, of what the dead friend was like and who freaked out at his funeral. And then a bittersweet realization strikes me.

The friend she lost has a story of his very own. It is the chronicle of one tragic death, with all of its intimate details and reverberations. His story will be repeated by the young woman for years, and by her brother and by the remaining loved ones of the absent friend. And they will grieve and remember this individual death and grant it the weight of a rare tragedy.

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I didn’t get many chances to do that, living as a young gay man in Los Angeles in the 1980s. There were very few singular deaths. It seemed like everyone was doing it. And among them, a dozen friends close to me, struck down within months of one another, with whom I shared a history of youthful secrets, joys and indiscretions, never to be spoken between us again.

Already I have indulged in a regrettable pastime that aggravates me when others pander to it. I am counting my lost friends like selfishly guarded chips in a morbid poker game, claiming my grief as if the high tally amplifies the legitimacy of my loss. There is no hierarchy of misery. The death of one person close to you is quite enough.

And yet there are harrowing, undeniable moments from my past, drawn from 30 years living with HIV, that have shaped my attitudes and the senseless tragedies that befall us.  I can conjure them but I must do it deliberately, for they are held captive in secluded corners of my mind and I release them with great caution. Perhaps now is the right time to unlock a few of those images.

The fluids in Lesley's dying body percolating like a coffee maker as we stood at his bedside awaiting his last breath. The anguished admission by my brother, Richard, that he helped his critically ill lover swallow a deadly, Seconal-laced cocktail in order for him to die on his own terms and avoid the final indignities of AIDS. My visit to Pablo in intensive care during his pitiful throes of dementia, nodding my head reassuringly as I tried to decipher his final, incoherent pleas.

They are a litany of despair, these heartrending tales, but I feel compelled to reveal them as part of another common exercise: to authenticate my history as a "long-term survivor." I have misgivings about that unsettling designation because it doesn't speak to my other, parallel life experiences and it suggests a dismissal of my relevance in the here and now.

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In the decades since those sorrowful days, I have faced a host of perilous circumstances apart from AIDS, including a car crash, drug addiction, serious medical procedures and weapons pointed in my direction. Like everyone else, positive and negative alike, I am a survivor of life itself.

That life has included falling in love, changing careers, teasing my friends, watching my cats wrestle one another, and looking forward to whatever lies ahead with a deep sense of gratitude and joyful anticipation.

And it is this prism—one that includes AIDS as only a segment of my life—through which I view the world today. My status as a long-term HIV survivor does not make me a champion or a museum piece to be examined and admired. I am a man in the prime of his life. My age and maturity guide me, not the virus that has failed miserably to kill me.

The grief-stricken young man I once was held no clue about the mystifying speed with which time passes. The swift interval between the early days of AIDS and merciful treatment breakthroughs confounds me even now. Suddenly I blinked, and when I opened my eyes I was 40 years old and the world was a far different place.

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Many of us remember that new world, when people with AIDS were saved by a miraculous “cocktail” of new medications. Living with HIV before the mid-1990s, when these medications were introduced, has become the popular line of demarcation for entry into the fellowship of long-term survivors.

My work in HIV advocacy continued during this time while others retreated to lives away from daily reminders of the epidemic. I did not fault them for that, in fact I envied them, but the army of our earliest activists, forged in the first years of the plague, had diminished.

By then, women and people of color had gained more traction and acknowledgment in the HIV arena, though without the national fervor or the generous support enjoyed by the original, largely gay agencies.

It was a time of such hope and encouraging progress, but if you scratched the surface of these victories you found they were dependent on privilege, money and access. Deaths continued unabated behind a dark curtain of racism and poverty.

The gay community began to avert its eyes from the continued infections of people unlike ourselves, and I joined many other exhausted activists who abandoned town hall forums devoted to HIV for the celebratory relief of the dance floor. Massive circuit party events became a vibrant diversion, summoning revelers by promoting their dubious contributions to AIDS service organizations. After a generation of relentless mortality I felt entitled to the party, to the steroids and the gym membership and the body-thumping beats of house music.

That is, until the festivities morphed into drug-fueled bacchanalias that required ambulances with the same regularity that had once been needed at AIDS hospices. I fell victim to their excesses, and my drug addiction and recovery process removed me from HIV advocacy for the next several years.

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I blinked again and now find myself here, sitting in my home office as a man in his 50s. My workspace is populated with relics of the epidemic, the walls filled with posters from AIDS Walks and photos of protests and triumphant arrests. A vast collection of name badges from AIDS conferences are strung from a single hook in an enormous, colorful bouquet. And everywhere around me are reminders of the missing. Pictures of friends whose faces will not age. Borrowed sweaters in the closet that need never be returned.

They comfort me, these tangible reminders of strife, victory, love and loss. They help me embrace and appreciate my life history. Perhaps I don’t find the title of “long-term survivor” so unsettling after all. There are worse things.

Most of all, the trauma that had once consumed me is now shrouded in the fog of a fading dream.

What remains are the wondrous developments of the present, like treatments that have also rendered people with HIV non-infectious and the amazing potential of pre-exposure prophylaxis (PrEP), a pill to prevent someone from contracting the virus. The advent of PrEP is the most significant prevention advancement in a generation. It is just the kind of miracle we once prayed for as we sat silently in pews at memorial services.

But astoundingly, these developments have been nearly as controversial as they have been celebrated.

There are thoughtful conversations about the cultural and medical effects of PrEP. What a shame they are being drowned out by clanging arguments about who is using condoms and who is not. The ludicrous chatter about who is a whore, a role model or a rebel foolishly reduces human sexual behavior to a problem that must be solved. Much of it seeks to impose sexual sterility in the way homophobic conservatives once denounced all gay bedroom antics, whether they were risky or not.

I remember what sex was like before gay men started using condoms. It was glorious. It still is. I always thought that finding our way back to enjoying sex without a barrier was kind of the point. Even the popular slang for sex without condoms, “barebacking,” evokes some kind of deviant sexual pathology. The entire history of human sexuality would suggest otherwise.

I watch the absurd finger-pointing today, the naïve segregation of positive and negative, the lack of empathy granted to human failings, the tendency of the newly infected to call the police before they call a doctor, the fracturing of the advocacy efforts built over decades, and I weep for the community we once were.

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Our hand-wringing over how to engage young people bemuses me, particularly our morbid fascination with aggressively foisting upon them the horrors we once endured, as if clubbing them with fear will somehow make them rethink their youthful transgressions. Our heartbreaking past is important history that should be preserved. It is not a prevention strategy.

Trying to imprint our life lessons on the young is a fool’s errand practiced without effect for millennia. I have never walked up to anyone who served in Vietnam and asked him to sit down and tell me all about it. I may respect the elderly soldiers in Veterans Day parades, but whatever post-traumatic disorders or multiple losses we may share fail to unite us. I watch them roll by in wheelchairs, festooned with medals and shriveled into nothingness, and then I have the audacity to wonder why younger gay men don’t consider my life experiences relevant.

Our influence as long-term survivors may be limited, but we can find meaning and engagement as cultural elders and mentors. To whatever degree younger people are receptive, we have so much to offer about the nuances of treatment, the various side effects and the failings of the

pharmaceutical complex that we have rallied against so effectively through the years.

Regardless, nothing should deter us from being of service to one another. We must support the emerging networks of other survivors and work to find solace in our shared history. We are a displaced segment of a community that once ministered to us. Our bond is vital to finding solutions to the issues we face as an aging population.

As wearying as our battles have been, as unwelcome as we may sometimes feel in the modern advocacy movement, we have plenty to contribute. We had better do it while we still can.

I am sensitive to the passage of time because I have seen lives with great promise left unfulfilled. I may no longer fear dying, but I am sorely afraid of not taking full advantage of these precious additional years that were once unimaginable. Regrets, the things unsaid and undone, are what frighten me and urge me onward.

The mysteries of life and time will be revealed in due course: to the woman on the bus grieving her singular loss, to those who would howl at the moon over behaviors they do not understand, to survivors grappling with the meaning of tragedy, to young people negotiating the sexual terrain, to you and to me and to all the rest.

Enlightenment awaits. All we have to do is blink.

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