Sean McKenna: Life with AIDS Isn't So Damn 'Fabulous'

April 22, 2017 By Mark S. King

Last December I attended the most moving, transcendent World AIDS Day program I have witnessed in years. That's not saying much, of course. These evenings are usually well-meaning but maudlin, featuring tearful eulogies while we hold up candles that drip on our fingers as we revisit personal losses that I put to rest a long time ago. Okay, clearly I have issues with grief.

But this event, organized by long-term AIDS survivor Sean McKenna in New York City, inspired and reawakened something in me. The program featured speakers and entertainers (this is New York, after all) who rose above the perfunctory nature of these events and made it something truly beautiful. It ached with loss, yes, but it also had an emotional honesty that never felt melodramatic. And it made me want to know Sean McKenna better.

I tend to present my life with joy and good humor (and let's face it, I have never had a challenging emotion that wasn't worth stuffing down as far as possible). Sean, on the other hand, wants us to face the harsh realities of today's long-term survivors. He has sent me messages to chastise me for painting too rosy a picture. He puts me on the defense a lot. In other words, Sean McKenna does exactly what a good advocate should do. He bears witness and holds people accountable.

In my interview with Sean, we wrangle over our different styles, the purpose of AIDS history, whether fear is a useful tool, and his insistence that life today for long-term survivors is far worse than any of us are acknowledging.

First of all, we have very different attitudes about being long-term survivors. I should probably say that up front. Would you agree?

Actually no, I agree with a great deal of what you say but there's nothing really 'fabulous' about it as we age.

Oh, so we're going to go there right away, eh? I will admit I was being cheeky when I named my blog My Fabulous Disease, but isn't there a place for some levity? And why shouldn't whatever joy and humor we possess accompany us as we age?

We wouldn't be here if we couldn't find joy or humor, and "fabulous" worked for me before my friends started getting ridiculous kidney problems and cancers. Before they became home bound by soft bones and the continued isolation. Some even opting out of their meds or not getting them

for cognitive reasons. I have great respect for what you do. The world needs both of us.

Sean McKennaAline Paley

You’re speaking up for those for whom decades of HIV hasn’t been easy, or at least it isn’t now.

I’m speaking for people who have recently lost their husbands and have to sell all of their belongings to be able to access the proper care. I’m speaking to people of color who have NEVER

been serviced correctly.

When I wrote the piece "Stop Bludgeoning Young Gay Men with Our AIDS Tragedy," you were offended. Like, really offended. I was making a point about respecting our history but not using it to shame younger people, but you weren't having it.

I was offended. You don't tell children to forget slavery, the Holocaust, Vietnam or any other world war. History is not about shame. I've never used our war on AIDS to shame anyone. In addition, I believe it gave a lot of younger folk the permission to not give a shit about those of us who paved the way for PrEP. It doesn't help garner respect for long-term survivors.

Yes, but did you ever, in your youth, ask a WWII veteran to sit down and tell you all about it? My own Dad was an Air Force colonel, and we never discussed the wars he fought in. I give younger people some slack on this topic. Human nature is self-centered. We have to experience life for ourselves.

I give younger folk more credit than that. My Uncle died in the Korean war, he was Dad's best friend. We were taught about it in schools, so yes, I was curious.

I know "the AIDS years" of the 1980s have shaped everything I am today, and I believe that history should be preserved. My objection is when we try to scare the hell out of younger people about those nightmare years so they will respect us more or change their risk behaviors. Scare tactics about the past don't work. If so, why would any new war begin?

When I was in school we had bomb drills. I was scared but it didn't change my history or the fact that it needs to be at least a reference. I have never tried to scare young people with our War.

I think our different points of view might be reduced to this: I see AIDS in the rear-view mirror. You see it in the passenger seat.

Unless I am misinformed and there is a cure, then you are in the driver's seat, too. I feel an obligation to communicate our history, not pretend it didn't happen for fear of scaring young people. Besides, Larry Kramer scared the shit out of a lot of people and boy, I am glad he did.

When I met Larry last month for the first time, to interview him for POZ Magazine, I couldn't bring myself to tell him I had a blog called My Fabulous Disease. Can you imagine his reaction? Oy.

You give people a laugh and hope and I respect that, but there isn't anything I'm afraid to tell Larry. He was not about laughs. I like to think he would be proud of my tenacity.

What do you want to see change? What rights and services are not being provided us, and do you mean long-term survivors specifically, or all people living with HIV?

Well even those that are positive now will someday be long-term survivors, no? I would like AIDS service organizations to realize that those of us who were given a death sentence in the 80's and

90’s are not doing so well. We didn’t have the advanced meds, we were the ones they tested them on. I can’t believe that you don’t know any long-term survivors from those days who are living in poverty and often times without any services at all. People with bone and cognitive issues, people who are homebound, because that is the reality of long-term survivors today and time is not on our side.

Actually, I know plenty of longtime survivors. We’re all doing well, although bone density issues have cropped up. That is probably more to do with my being a privileged gay white man, I imagine, with access and resources.

I have heard of too many early deaths, be it from side effects or just giving up and I hear of more every day. It is because of constant needling of the GMHC that they now have a working Buddy Program and are creating a Long-Term Survivor Hub, that and (GMHC Executive Director) Kelsey Louie’s willingness to listen to me. (Sean convinced GMHC to reinstate its Buddy Program in 2015, specifically to offer support to long-term survivors.)

At community-based events like Positive Living (the last remaining weekend conference/retreat for and by people living with HIV/AIDS), I get to hang out with a much more diverse collection of people living with HIV. And yes, they are struggling. It is happening behind a dark curtain of racism and poverty.

That curtain needs desperately to be lifted as we are dying again. Some of my friends say it’s like the 80’s all over again.

The 80s? In what way? Do you believe that? It feels extreme. As someone else who was there, today ain’t nothing like the parade of funerals we had then.

We may not be dying in the numbers that we were in the 80’s, but the stigma, lack of services, lack of someone to listen and help, is too close to what happened in those early years. We’re losing each other when we should be serviced and respected. So yes, in many ways it’s just like the 80’s. We watch the fortunate survivors thrive while having arthritis at 40 or 50 years old, which is not normal, makes it hard to even get out of bed. Support groups have dried up, not that we can all get to them. The difference between now and the 80’s, besides numbers, is that nobody is desperately trying to save us like back then.

I want to hear more about this, because I think it would surprise a lot of people. Please say more about longtime survivors who are homebound, dying of side effects or giving up. I don’t think it is the dominant view, although social stigma is another thing altogether.

So many of my friends have lost their insurance and are now living on disability alone. You can’t live a healthy life on that amount of money. Too many have written to tell me they’ve given up. Too many have died most recently in their 50’s and 60’s whether it be heart attacks caused by the med side effects or cancers that we are 40% more likely to get. It’s a bleak existence, living below the poverty level, having cognitive issues at an early age and trying to understand a system that is quite happy to lose us.

I do believe a lot of people would prefer that long-term survivors hurry up and die already. I mention this specifically in an article on HIV stigma I wrote for POZ Magazine, saying, “They remind us of our darkest days, these unwelcome relics, and though we ignore them their haunting persists, in the daylight of the grocery store and the darkness of the bars. We avert our eyes and anticipate their extinction.”

I couldn’t agree more with your quote. We are a reminder of those dark days but that is no reason for our community to sweep us under the rug. We’re just like you said, "unwelcome relics.” Certainly not what veterans of a war deserve.

Who else is addressing the plight of longtime survivors in ways you admire? Any programs or organizations that are handling these issues well?

Tez Anderson in San Francisco, founder of Let’s Kick ASS (AIDS Survivor Syndrome) is to be admired, and some healthier long-term survivors are waking up to it but that is it, other than what I talked GMHC into doing, and that’s a crime. (NOTE: Watch the “Definition of Brave” Town Hall Forum in San Francisco, about long-term survivors, below.)

There’s only one person who comes to mind who is addressing the issues of longtime survivors? That suggests there isn’t a lot going on, or you’re not exactly impressed with what is.

There are a handful of us but cognitive issues is one of my most embarrassing traits so I’m sure I’m forgetting people.

Let me plug some folks I appreciate in this arena. I like the Reunion Project out of Chicago by TPAN, which has been holding events in major cities, and the recent Seniors with HIV conference in Ft Lauderdale sponsored by SunServe. I do see HIV media making aging with HIV a hot topic: stories about our unique challenges are on every HIV site, and Positively Aware just devoted an entire issue to it. Now, some of these are specific to longtime survivors and some are more generally about aging with HIV, but it’s happening. I see people like Tez, Matt Sharp, Jeff Berry, Sean Strub, Rae Lewis-Thornton, Greg Cassin and others as being pretty forward thinking on this.

Let’s just say I started talking about it four years ago. That’s lives lost in the meantime. I agree that we are more in the public eye but it’s one thing to be talked about, another to be serviced.

So what, then, would you like to see being done? What programs need to be offered, and by whom?

I want respect and services before we die. I want services for homebound long-term survivors. I’m quite proud of how GMHC is following through on this. But many of these agencies are focused on PrEP, trans rights, etc., which are all admirable and all necessary. Just don’t toss us aside.

There is a real poignancy in your saying “I want respect,” Sean. You’ve mentioned it a few times. I share that sense of wanting due respect, for what we endured and what we accomplished as a community 30 years ago. That said, no one has much use for the past, it seems. I’m talking about

people generally, but even younger, newly diagnosed HIV positive people. They've got their own challenges, their own lives to lead. We're not great at looking backward as a species. Which is where this conversation began, actually.

If we ignore history we are doomed to repeat it. There are ways to educate younger people without scaring the crap out of them and maybe in this day and age of immediate gratification we should pause and look back once in a while. I want to thank you too for keeping our spirits afloat with your blog for those years that we didn't foresee these consequences.

Well, I'm both more optimistic and more cynical than you. I think the world today is a far better place for people living with HIV than it once was, but I don't think people care about history all that much. Most everyone who reads this will be long-term survivor themselves. Most others will scroll right past.

Not true, you would be surprised but time will tell.

Okay, you're a hard nut to crack but I admire your tenacity. We share a very close DNA strand about these things. Let's be friends.

I thought we were!

Well, we've never done lunch. That's a requirement.

Lunch is on, but you're paying.

Done.

Thanks very much! And now I've made it on your blog.

My pleasure. But I'm not changing the name.

Mark

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