The Return of Spencer Cox

A friend of the late activist invites you to a community discussion on improving the mental health of AIDS survivors.

April 25, 2013 By Carly Sommerstein

Spencer Cox

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My friend Spencer Cox could see into the future. In his work for the Medius Institute for Gay Men's Health (started with his good friend John Voelcker), Spencer was acutely concerned with the profound psychological impact of the AIDS epidemic and the short- and long-term effects of depression on the lives of survivors.

He wrote two fascinating white papers—The Legacy of the Past: Gay Men in Midlife and the Impact of HIV/AIDS and Living on the Edge: Gay Men, Depression, and Risk-Taking Behaviors—that artfully addressed the issues of depression, post traumatic stress disorder (PTSD), loneliness, drug use and unsafe sex practices in gay men.

His conclusions: Our brave surviving brothers (and sisters, because I believe Spencer would have expanded his research and studies had he had the chance) who are struggling need more and more-effective mental health programs to address depression not as an isolated concern, but within the larger and complicated arcs of gay life today.

His recommendations: "Improved access to mental health specialists is specifically needed for HIV-positive gay men....Unmet health-care needs are helping to create [a] cycle of crises. Longer-term solutions are called for." Though Spencer anticipated and wrote beautifully about the need for AIDS survivors to have access to specialized mental health care, he was not able to clearly see in his own life how necessary this help was.

We know this because he made a conscious decision to go off his antiretroviral (ARV) medications, tragically leading to his final hospitalization with pneumonia. And I know this because we had spoken about depression in the months before he became ill and because I spent the last days of his life with him.

Spencer loved New York City with all his heart. Upon his return after many years in Atlanta, when once again forced to smell that all-too-well-known pee odor of our subways, instead of complaining, he once

exclaimed: "Ah, l’eau d’ urine—bitches, I am BACK!"

He was purely happy to be "home," but that did not mean he did not have some real struggles, emotional, physical, and financial, to name but a few. He was not well enough to work yet, but his generous mother had filled a little bank account for him, so he did not have to go without food, and his meds were being paid for, yet he felt bad about not being able to treat his friends when going out.

Speaking for myself, and I know for all who knew and adored him, we were absolutely delighted to pay his way. And that boy did love a good steak dinner. But he felt he should be able to shell out even a little money. (If I had ever called Spencer "a Southern gentleman," he would have verbally thumped me, but he was that.)

The Sunday before Thanksgiving of 2012, I took Spencer out for lunch (to Chat ’N Chew!) and a movie (the Hitchcock biopic; Vertigo was his all-time favorite movie, but we were kind of "meh" on this one). Over burgers, he asked me how I was feeling and I asked him the same. We were both having health struggles and so we both answered each other the same way: Not so great.

Spencer intuited that I was struggling with low-grade depression, which he called "situational," and suggested that I seek help. (If my darling Spencer had trouble seeing clearly for himself, he could always see things clearly for me, and found me the right doctors so that I would eventually recover.)

We talked a bit about how hard it was to live "with all the veils removed," which was his way of explaining what it was like to live knowing that your health might never totally improve, that your struggle with physical pain and exhaustion may end only with your death. Spencer was struggling but he wanted to go on, most sincerely so.

The disconnect between intentionally going off his ARVs and the note of frustration and hope he wrote me the first day he was hospitalized is heartbreaking (writing was necessitated by the breathing mask he needed for pneumonia; I wrote him back as a matter of privacy as a nurse was entering the room):

Spencer: It’s been such an awful 2 wks. Nothing that happens makes sense, I feel awful...

Me: How can I help you? Should I contact your mother or brother? I cannot make medical decisions for you but I will help you in any way I can. (Spencer did designate me as his health-care proxy after this conversation.)

Spencer: Not Mother yet. I will give you her #, though.

I am

-scared

-baffled

Whenever I try to do something good

He stopped there. It was too great an effort for him to continue to write, so I finished his thought for him aloud: "Whenever you try to do something good, you get sick over and over again and it is so, so hard. I know, sweetie." And I held his hand for a long while.

(The piece of paper Spencer wrote this note on? An article from The Atlantic that I had printed out for him, planning to read it to him that day: "The Sex Lives of Conjoined Twins" by Alice Dreger: "Why does the topic ’defy imagination’?" I did read it to him and he loved it, of course.)

Lee Raines, a dear friend of Spencer’s, told me the last time they were together, they were walking along East 14th Street in Manhattan and Spencer was belting out a show tune: "I Have Confidence" from The Sound of Music. I love the memory of that display, courageous and fun-loving Spencer all the way (he always called himself a "show mo").

I have so much rachmones [Yiddish for compassion] for his tough, long fight for health. "Unless you’ve been taking the full battery of HIV medication, you don’t know how hard it can be to stay on your protocol," is how one friend has explained it to me. And another friend, no stranger to profound depression, explained it to me this way: "Carly, you have no idea, in the fight against depression, how easy it would be to just GIVE UP. To stop fighting."

Spencer should have grown old in the city he loved, but he needed more help. He needed more advocacy, and he had a right to that advocacy, and not only because he was a national treasure. As his obituaries state, with his work in ACT UP and the Treatment Action Group (TAG), Spencer helped push key drugs into the world, saving myriad lives.

Spencer was proud of his work, and with the Medius Institute, he sought a way to address important issues, but he could not find adequate funding to continue his work. That was something that broke his heart at the time, he would later confess to me. He was a man who in 2006 proactively saw a need, who was loved by many and whose memorial was attended by hundreds of people, but who could not find a way to reach out for the help he required.

The Bette Davis of the World of HIV did not get to live as long as he should have, and not nearly as long as Bette herself (with whom he shared an incredible toughness and with whom I know he is now smoking a cigarette and snort-laughing).

At the end of 2012, we lost Spencer Cox. I lost my darling.

Do you know someone from the AIDS Generation, perhaps your darling? Your national treasure? Are YOU that person? In losing someone dear to you or so many dear ones, is the hard lump of grief you carry some days too much to bear?

Many of our friends and loved ones may today find themselves in the same place as Spencer. We don't know nearly enough about an entire generation that lived through the Plague Years—the righteous, the joyful, the struggling as well as the thriving—and it's time to hear from them and to address their issues.

Please join us May 9 at Baruch College in New York City for a community discussion. You have a right to more and better advocacy. We are the Medius Working Group—we seek to revive Spencer's work and we seek forward motion always.

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