Read This: Heroic Measures

In A Fragile Circle, Mark Senak closes his with memories of the early days

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We find strength for future challenges by looking to the heroism of the past. In a review of a recent edition of *The Diary of Anne Frank*, Patricia Hempl quoted the education minister of the Dutch government in exile: “History cannot be written on the basis of official decisions and documents alone. If your descendants are to understand fully what we as a nation have had to endure and overcome during these years, what we need are ordinary documents -- a diary, letters.” This principle is as relevant today as it was in 1944. We must record exactly what it was like to live through one of the most extraordinary events of the 20th century -- the AIDS epidemic. But the early days stand in danger of being forgotten. In the face of idle promises and indifference, an entire people rose up to care for themselves by creating AIDS service organizations and becoming activists. The events are there for posterity, recorded in newspapers and books such as *And the Band Played On*, but such sources do not, on their own, tell the story. There aren’t many witnesses left. Mark Senak, a gay man and lawyer, joined 17 other staffers at Gay Men’s Health Crisis (GMHC) in 1982. Of those 18 people, only six are alive. Now Senak has written us a long letter home from the front lines of the silent war of AIDS.

-- From Steve Tisch’s foreword

EXCERPT

In 1984, the fear that clung the hardest to me was of Kaposi’s sarcoma (KS). It was the meanest opportunistic infection (OI) I then thought could exist. As it turns out, I was wrong about that. I have seen PML reduce a beautiful athlete to a vegetative, bedridden state in as little as four months. But in 1984, PWAs rarely survived long enough to get OIs other than KS and PCP.

I was called to the home of a man named Richard for a deathbed signing [of his last will and testament]. In the center of the living room was a hospital bed with a large man in it. He was barely wearing any pajamas, though his torso was covered. It appeared as if he had no skin. His eyes met mine from a pool of swollen, red scabs that distorted his features. It was impossible to tell what he had once looked like. The scabs and lesions traveled down his powerfully girded arms, and his bare legs -- propped up on pillows on the bed -- were swollen masses of decaying flesh. There was a nauseating smell of decay. Richard had little or none of his nose left. He was literally rotting away.

I had never imagined KS could take so much of a person without first killing him. But apparently

Richard’s internal organs were untouched. He still had a hearty appetite and was not weak.

Richard’s eyes never left mine. He scrutinized me carefully for my reaction to his appearance. I wish I could say that I handled this so well we were laughing by the end of it. But I was nervous. I trembled slightly. But as much as I wanted to stare at anything else in the room, I tried not to let my eyes leave Richard’s.

Allen [Richard’s lover] introduced me and I put my hand out to grasp Richard’s. It was an effort not to wipe my hand on my pants, not to shiver, not to look away. Nevertheless, I hated myself for what weakness was showing through. I felt like Richard hated me for it too. His eyes returned a challenging gaze, as if he were daring me, to see how long I could look at him without an overt signal of my revulsion. We didn’t really speak, he merely acknowledged my recitation of the instruments I had brought for him to sign.

A few days later, Richard’s legs were amputated. I never saw him again. I remember uttering the words Thank God when I saw Richard’s name on my RIP sheet. However, Richard’s face would visit me many times after that. Late at night, alone in my bed, his eyes would stare again into my own with his challenging expression, while I lay wondering if there was a virus in my body eating away my immune system, waiting to steal my youth and looks and happiness as it had done to Richard. Each time, I tried to push him further away. But Richard will never leave me.

Joe Foulon and I were invited to a Martha Graham Company dance performance. I waited outside and saw Joe walking up the street with an air of casual elegance. It looked as if his clothes had been made only for him. After the performance, we went to dinner and then back to my apartment. Sitting on the couch, we talked until late into the night. And then he kissed me.

After some time, we sat with our arms around each other, not saying anything. I reached over and whispered in his ear to ask if he would like to stay over. He held me close and was quiet. Then he whispered in my ear that he hadn’t been with a “well person” since he had been diagnosed. Whispering like this seemed to be the only way we could have this conversation. I thought about what he had said. I told him that I had never been with a “sick person” either, getting a little hung up on those words. We paused and then he began to remove my clothing and removed his. He turned and walked up the stairway to my bed. I can remember the sight of his silky, smooth back and my feeling of relief and the burial of my fear -- and we went to bed. It was a wonderful night, and in the dark I couldn’t see any small lesion, nor the threats involved in sleeping with someone with AIDS. For a night we could just forget about everything else and hide it all in the dark while we explored each other’s bodies and passion.

In the morning my eyes opened with a start. Up until now, I had worried about everyone I had ever been with -- did they have AIDS and could I have gotten it? Now, here I was, falling in love with someone who was going to die. I will never know the reason, but the fear about past boyfriends never came back to me again. I wasn’t afraid about getting AIDS from Joe; I was afraid I would lose him. This began the most wonderful and awful time of my life.

Six months after I began working at GMHC, in October 1985, I got a call from the producer of

Oprah. He said that they were doing a show on AIDS discrimination and asked if I would be on the panel of guests. Other guests were Bobby Reynolds, a gay PWA activist from San Francisco, and a 12-year-old boy from Indiana named Ryan White. As it turned out, Ryan fell ill and was unable to be there.

When I arrived, I discovered that the producer, Bill Rizzo, was the same Billy Rizzo I had dated in college. We had both grown up a bit but not so much that we didn't scream when we saw each other. Years later, Billy died, and I had heard that Oprah had been close to him, so I sent her a note, but I got back a white card with a handwritten "Nice to hear from you!" which is, I guess, what most people get because it didn't seem an appropriate response to a sympathy note. Amy Sloan, an Indiana housewife, was taking Ryan's place on the show. In the early '80s, Amy had needed a transfusion during a medical procedure. One of the units of blood she received had been donated by a gay man who had the virus. It was before the HIV antibody test was developed to screen blood. Years later, Amy found out she was pregnant. A day after the happy news, she got the bad news. The doctors told Amy she had AIDS. Amy was then faced with a terrible decision, one that was rare in 1985. Amy chose to have her baby. Brandon was born HIV negative. Amy was 24.

Though a physical contrast to Bobby Reynolds, they spoke the same language. Oprah used the term AIDS victim. She asked, "Do you feel like a victim?" "I don't like the word victim," said Amy. Bobby nodded. "A lot of times when people use that word they treat me like an innocent victim. We are all battling the same thing," she said. "We are all innocent."

Call-in talk shows do not bring to the fore the nation's most enlightened group of people. *Oprah* was no exception. One caller stated, "I'm just upset about everything that's happened. I'm pretty open-minded, but I think something should be done about the gays. They are not coming up with anything quick enough. They prosecute drunk drivers. They are going to need to prosecute gays for spreading AIDS. I'm afraid to leave my home." This woman represented everything that was typical in the face of the epidemic. She was afraid and she was reacting out of fear. She blamed gays, yet Amy, with so much at risk, did not. The scariest thing in this statement, however, was that the woman considered herself "open-minded." Then she asked something that was often asked by frightened people: "Why don't we have quarantines?"

"Because, we're not gonna do it. I'm not gonna let someone quarantine me," shouted Amy. Amy was a great AIDS activist. She could say everything clearly and plainly in language everyone could understand.

One day at work as I was walking to my office, Kevin stopped me. "Darling, could you come into my office for a moment?" he asked. We went in and he sat at his desk. "Forgive me for this," he said. "I'm sure people do this sort of thing to you all the time, but I figure since you live with Joe, you could tell me about this." He shut the door to his office and began to unbutton his shirt. I still did not know what the hell was going on. Once undone all the way, he pulled open his shirt to reveal his right pectoral.

“Is this KS?” he asked. We had all been through this so many times. Gay doctors were busy answering this question about bruises and scrapes and dermatological abnormalities. The response usually was “No. That isn’t KS. You are being ridiculous -- it’s a bruise, silly.”

But I looked at Kevin’s lesion and knew immediately that it was KS. There was no question at all in my mind. Kevin was right: In living with Joe, I was able to spot KS in a New York second. There were times on the subway when I would examine marks on my fellow passengers, now and then finding a KS lesion on the back of someone’s neck, and wonder if they knew about it yet.

What could I say to Kevin? As sure as I was, I wasn’t about to go out on a limb and tell him he had it. “Well,” I said, “you know, Kevin, you would be real justified in calling your doctor and asking him to biopsy that for you.”

“So you think it is?”

“I think it’s worth finding out.”

His soft brown eyes looked at my face for an answer. I was determined to give him none. Kevin found out he did have KS. He asked me to do his will and he died not long afterward. My friend Rick Croll took his place as volunteer coordinator. Sadly, that was often the way promotions took place at GMHC.

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