Life: Hospitals Are Our Jails

The time for madness is now

December 1, 1994 By Kiki Mason

A friend of mine recently came home from a year in jail. A high-powered attorney in his fifties, an affluent white man, part of the country's elite, he isn't what I think of as your average prisoner. He wasn't jailed in one of those white-collar "country clubs" but in a real prison. And when he came out, my friend had stories to tell. He told tales of murder and revenge, incredible hypocrisy and everyday brutality, even moments of fleeting camaraderie and beauty, although these were tempered by the knowledge that survival may be just a matter of sheer luck.

As he spoke, I was struck by the similarities to the many stories I have heard from PWAs over the years, especially once they're trapped in the hospital system. His struggle reminded me of my own ongoing battle with doctors, hospitals and drug companies, because when you have AIDS, you're not just battling a deadly disease, you're up against a system that expects you to fail.

This country escalates prison spending regularly. We now have the highest incarceration rate in the world but we're still not safe on the streets. Likewise, medical costs skyrocket while more and more of us sicken and die even while listening to round after round of meaningless healthcare reform proposals that drop out of the sky as if from the Wizard of Oz.

I recently went to visit a friend in the hospital -- something I rarely do, so great is my hatred for these institutions. My friend, tubes hooked to his arms, was in a room with someone he clearly loathed. Between the lack of privacy and the demands of the nursing staff, he barely got any sleep and, of course, the food was almost inedible. His entire life was regulated "for his own good." The medical system, not unlike our corrections facilities, is about losing control of one's self. Someone else has the power, and in a hospital setting, you can never forget it. How is anyone supposed to get better in this kind of environment?

"You know, my doctor comes to see me," my friend says, "and I know that he's a good guy and he means well, but I see him wearing Versace suits and driving a Mercedes, and I wonder. I could die tomorrow, and he'll still be rich." Which is true. We could all die tomorrow and not one doctor would be out of business, because there will always be more sick people.

Even if you're not physically in a hospital, the system and your disease imprison you. Every decision becomes predicated on your health, forcing you to play "Mother, may I?" with the folks in

white coats. Endless bureaucrats make decisions that could kill you. For the past year, I have been at the mercy of a company in Menlo Park, California, known as Liposome Technology Incorporated (LTI). LTI makes a new, patented, less-toxic form of chemotherapy specifically developed for Kaposi's sarcoma (KS), which I suffer from. But I can't get their drug, DOX/SL, because it's in the FDA approval process and is available only to those who've failed standard chemotherapies, with their ghastly side effects. So while I have had to endure the horrors of chemo, FDA officials, the officers of LTI (and their mostly gay publicists) -- my jailers -- can go home and eat dinner in peace.

What I have noticed about everyone in the medical system is that someone else is always to blame. In a vast bureaucracy, no one is killing you directly, they're just following orders. The round-robin of finger pointing is endless, although the end result -- death -- is always the same.

Yet when you say these things aloud, as I frequently do, everyone looks at you with a certain patience, as if you had gone quite insane and must be humored. When I hear that someone has dementia, I wonder is it organic or was he driven to it? When I recently read a nurse about a filthy hospital room, she called me "hysterical." Well, back at you, baby. "Sweetheart," I told her, "if you think *that* was hysterical, you'd better batten down the hatches, 'cause when I really let go, you'll see some real howling." And I mean it.

In reality, we're all in prison. A prison of our expectations and of the society we have built around us. Our society benefits from our tacit approval, and the horrors of the committed, whether to a prison or a hospital room, are erected in our name. Most of us don't think about what we're truly up against. That would be madness. Well, maybe it's time to go mad. Join me, if you dare.

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