HIV and Me

Even long-term nonprogressors get the blues

December 1, 1998 By Mike DeStefano

What the hell am I doing writing a column in an AIDS magazine? I'm not even a real HIV dude. I'm a fake, a fraud, what they call a *long-term nonprogressor*.

I just got off the phone with the doctor; it's that time of year again: test results. "How are you?" he always asks me first. "Wonderful," I always reply, because that's what I'm supposed to say, given my blessed health status.

Every six months for the last 10 years, it's the same story: I go to his office, give blood and spend the next two weeks freaking out while waiting for the bad news. Guess what happens? Nothing. Not a damn thing. I haven't had a single sign of progression. My CD4 count is 1,400. Yep, one thousand four hundred. Viral load: zip, zilch, undetectable.

Now, don't mistake me for a Lazarus. I've never taken a single antiretroviral drug, and I've been sick only once in the past decade. In the hospital with pneumonia, I lay there thinking, "Here we go: weight loss, lymphoma, AIDS, dementia…" But all that happened was, I lost three weeks' pay.

In the beginning, when AIDS was an automatic death sentence, I was crippled by the fear of progression. Every sneeze, cough and pimple brought me closer to the hospice door. I diagnosed myself with every major opportunistic infection, even cervical cancer. It was hell. I spent weeks, then months, then years in the dark, waiting to get sick. Finally, I couldn't take it anymore, so I studied Buddhist meditation for two years to make peace with my mortality.

And now I'm paying off the farm on installment plans. I finally accepted death, and what did I get? Life. A life of chronic low-grade sadness spiked by fear and uncertainty. You think it's easy being HIV healthy while watching friends die? There were times I would have gladly traded places with my dying wife to end her suffering, not just because I loved her but because I wanted it over with. Now she's gone, and I'm still here.

What is going on inside my body? They say maybe I have a special gene, gp120 or something. Is mine a rare strain of virus that's harmless and can't be transmitted? Is this happening because of my Mafia connections? If only I knew, I could get off this fence. It's weird enough trying to fit into regular society as a person with HIV, but it's a real bitch not fitting in with the AIDS community.

When I talk to groups of people with HIV about my health, they ask, “What’s your secret?” I tell them I don’t have one. I do nothing special—no super green algae, no coffee enemas, no Deepak Chopra. I don’t chant “Om” or sit on the beach with crystals up my ass. I eat whatever I feel like eating, drink coffee like it’s going out of style, smoke two packs of Marlboros a day and have an attitude problem. I just don’t know.

What I do know is that hiv (I’m not capitalizing it anymore) has been 100 percent psychological for me: the mind-fuck of my life. But hey, I shouldn’t complain, right? I should just be grateful. For a life that feels like a consolation prize? I’m like one of those pathetic game-show contestants who gets a year’s supply of Spam. I may be more alive now than ever, but guess what I get? All the usual stigma and ignorance, and the fear that women have of my phantom hiv. Can I have a child? I bet I can, naturally, without infecting the woman or the baby. But who would believe me?

Before hanging up the phone with my doc, I lit a cigarette and immediately began coughing—smoker’s hack. For the first time I heard myself say to him, “I better quit these things before they kill me.” We laughed, contemplating my surviving AIDS only to die from lung cancer or emphysema. As twisted as it may seem, the thought brought a smile to my face.

Still, what a pain in the ass this little piece of paper has been—the positive test result that has taken me through emotions I never even knew existed. And most frustrating of all, I know in my heart of hearts that because of these years of turmoil, I’ve become a pretty decent guy. It kills me to admit it, but somehow I needed this virus. So please forgive me, those of you who have been or are sick: I’m not spitting in the face of grace. It’s just been one of those decades.

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