Dead Gorgeous

Is it so wrong to be the picture of health and a PWA?

March 1, 1997 By Mark Matousek

The first thing my British publisher says to me when we meet is, “But you look fine!” She’s pleased when she says it, but also confused. She has, after all, bought a book about someone who’s had this virus for 15 years. Maybe she expected my lover and me to roll into the hotel lobby in matching wheelchairs; maybe she had braced herself, before our first dinner meeting, for two hours of staring death in the face; maybe she was even scared. Whatever the case, she was clearly amazed to see that not only were Louis and I ambulatory, but we had suntans, muscular thighs and appetites like hyenas. In short, we did not *appear* to be dying.

Although such confusion wasn’t new to me, the common misconception of what an infected person is supposed to look like had come into sharper focus since I’d started my publicity tour this year. It didn’t seem to matter that I’d never been sick a day from this thing; that my book focused more on spiritual questions than on viral ones, and on Mortality with a capital M (as in existential concern) rather than on this puny, nasty bug.

In the public eye, HIV seemed to be (annoyingly) the point, the lens through which one was viewed, heard, questioned and read. Though the virus was far from the most interesting thing about me or my story, I’d learned quickly that when AIDS is in the picture, it tends to wipe everything else away, like a petty tyrant, reducing a person to the sum of his or her microbes. Having written an honest book in part about being positive, I’d placed myself in the public view, squarely in the heap of dying people-the have-nots, the poor things, the victims. That I was not visibly impaired perplexed them and was even, for a few, slightly disapointing.

Mostly people were fascinated, however, especially in such places as Aukland and Minneapolis, and looked at me as if I were some sort of phenomenon, like that woman embraced by the light, or the author of *Alive*! who’d eaten human flesh and lived to sell the film rights.

Many of them had never before seen what an actual long-term surviving asymtomatic person with HIV looks like. (Just like them!) Till now, all they’ve heard was that party line that AIDS kills, that people with the virus are obviously sick. Many did not seem to know that even as they sat there in the bookstore, the epidemic was being redefined as largely treatable, tranformed from the black-and-scarlet acronym to something less terrifying (I vote for “lowered immunity”).

Though I was there ostensibly to sell books, I'd begun to see that I was also there on a subtle and subversive mission: As walking evidence that they'd been lied to, as a flesh-and-blood image of well-being to replace the doomed on they'd been carrying for a decade.

This sounds grandiose; it wasn't, nor was it intentional. The last thing I wanted to be was an AIDS activist; in fact, it pissed me off to be set apart from the common run of nonfiction writers (who are, apparently, immortal) just because I was positive. Still, I saw that the best I could do was accept this weird status as shamelessly as possible and flaunt it.

On radio shows where audiences couldn't see for themselves, I made a point of letting them know I was still intact, still working out, still getting laid. I played up this hail-fellow-well-met thing to a disgusting degree (in fact, Louis and I are still the neurotic whack-jobs we've always been), but in the face of ignorance, extra-normal propaganda was appropriate.

Odd, too, that looks should have so much to do with it; that the frightened public needs someone who looks well to open the world of AIDS to them in a bearable way. It's why "straight-looking" people are sometimes more effective crossover voice for gay rights than screaming queens with bullet bras. Healthy-looking people are the big raspberry in the face of the six o'clock news. We're the ones lucky enough to stand strong for years in spite of statistics and prophets of gloom, booming the verdict that we didn't have a chance in hell; the ones who can now stick our tongues out and say, "I told you so!" We get the laurels, at least for a minute, and the satisfaction of saying to people surprised that we look well, "Thanks, but what's the big deal?"

After all the pain, it's good to have a victory; it's good to have the vision of a possible future. The trouble is that now I've got to write another book.

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