Tools of the Trade

Karen Lyons has a hammer, and she's knocking down walls in Philadelphia

March 1, 1997 By River Huston

I first saw Karen Lyons at the 11th International Conference on HIV/AIDS in Vancouver this past July. Once again, the women were relegated to a place outside the mainstream events. We gathered as an international community and broke down by region. As I sat across from Karen in the North American group, I remember hoping that this time everybody would not end up going over the same old laundry list.

Karen was the first to speak: "Our issues are complex because of political red tape and racism. The people in charge of services are all about prestige and money. While they are making $70,000 to $100,000 a year, people are struggling with basic human needs such as adequate housing. These barriers make it hard to access the simplest services."

I had heard all these issues voiced before, but Karen made me listen. She has a strength and grace that inspires you to continue the battle no matter how tired and frustrated you get. All I could think of as she spoke was that I needed to know this woman.

Months later, after the excitement of the conference had ended, Karen and I spoke again in Philadelphia, and I was able to truly understand the depth of her fatigue and frustration.

Karen lost her wife of three years to cancer -- Rhonda died in May 1995. I had also lost a spouse, as well as so many friends, and I was deeply moved by the tenderness in her experience.

"Rhonda passed away in our apartment. I had never been with someone when they took their last breath. Just to watch someone so vibrant and energetic become unable to brush her teeth -- it was the first time I truly experienced powerlessness. I was still hoping that maybe something would save her. We could see the tumors coming out of her skin. She said she could feel them all on the inside."

Sometimes you think you have cried all your tears, but as Karen told me about her loss, I found myself grieving again. "I didn't want her to die alone, so I went and [brought her home] from the hospital. I sent for her kids. I held her hand and told her it was OK, it was time to go. Even though she could barely speak, she yelled out, 'No!' I put on some Babyface and dimmed the lights and she took her last breath."

Karen was left in emotional turmoil. A mouthful of thrush landed her in the hospital, with doctors fearing MAC. It turned out just to be stress.

“I learned a lesson through that,” Karen says. “I need to get away, relax, forget all this. I want to go to Disney World, somewhere fun, far away from faxes, telephones, meetings and AIDS. Besides, it is still going to be going on when I am dead and gone.”

But the urgency of AIDS and the needs of the community are like a siren song to an activist as dedicated as Karen. She is a member of the boards of We the People and the AIDS Consortium, a representative of Philadelphia Fight, and a founding member of WISDOM (Women with Immune System Disorders Organizing and Meeting). She works at Voyager House as a group facilitator for HIV positive youth and is the night outreach coordinator for the Youth House Empowerment Project. She has little time for rest with all these barriers to bring down. Her agenda for the next day made me tired; it was packed late into the night with more meetings on the need to make programs accessible and information understandable, on the need to bring the walls down for others, as well as herself.

The barriers don’t crumble easily, and Karen is characteristically blunt: “I am black in white America, a woman in a man’s world, a lesbian in a heterosexual world, and on top of it all, I am a lesbian with AIDS.”

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