Editor’s Letter

Killing Time

September 1, 2008 By Regan Hofmann

Somehow, I’ve managed to live with HIV for nearly 12 years without ending up in the hospital—for any reason. Until recently, that is. After I felt a sharp pain in my knee, a friend drove me to the ER, where I was admitted for what was a very nasty staph infection.

Listening to the cheerful banter of the doctors and nurses as they checked me in, I figured I’d be out in a flash. But as the hours, and then the days, passed, I wondered whether I’d get out at all. We had to wait for the culture of fluid drained from my knee to grow—so the docs could determine which antibiotics I needed. As my leg swelled and my temperature climbed, I felt a fear I hadn’t known since the early days of my diagnosis: the fear that I’d die, even under top-notch medical care. Without sleep or much food, dehydrated, my temp at 104 and my pain flaring despite morphine, I questioned whether I’d survive the surgery I required to fix my knee. The night before they operated, as I tossed and turned in agony, I yelled at the nurse, “I’m in a hospital in a developed nation—I can’t possibly have to be in this much pain!” But I’d already had my recommended daily allowance of painkillers, and the nurses weren’t giving me any more that night.

So I covered my body in small bags of ice, killing time by watching old movies and then turning to e-mail. I was feeling pretty sorry for myself. Until I opened an e-mail from our editor Nicole Joseph. As I read her feature story about Puerto Rico’s AIDS crisis (“The Castaways,”) I forgot my pain. The story begins with the tragic account of Ariel Fernandez, an AIDS patient who was left to die in a San Juan hospital by doctors and nurses who were afraid to touch him or give him any meds—believing that they would contract HIV. I suddenly felt ashamed for complaining. I was armed with info (I whipped out my laptop and Googled my doctors, researched their approach to treatment, and read out loud to them the side effects of the antibiotics they were pumping into me). I was capable of advocating for myself.

But in Puerto Rico, a lack of infrastructure, bureaucracy, mismanagement of AIDS funds, and stigma all conspire to keep people there living with HIV out of the reach of care and in constant pain. Lying on my crisp sheets, I felt a sense of the panic and despair that comes from being in a downward spiral of illness paired with uncertainty. But I was nowhere near the danger zone in which too many HIV-positive people live—and die—every day. Appreciating anew my relatively safe surroundings, I asked myself: Why are Puerto Ricans with HIV/AIDS still dying today, when we

have treatment that can help save their lives?

As I lay in my hospital bed the final night of my stay, ringing the nurse call button to no avail, I tried to imagine how Ariel Fernandez must have felt, waiting for help that never came. When my night nurse finally did appear, I asked her to help lift my leg out of bed and swing it to the floor so I could go brush my teeth. I was all hooked up to tubes and needles and was very wobbly on my crutches. When the nurse wouldn't touch me, I asked whether she was uncomfortable because I am HIV positive. "A little," she said. And as she watched me struggle across the room on my own, feigning concern, I said, "You know, shame shouldn't be placed on people with HIV, it should be placed on those who refuse to help us."

She left in a huff, and I struggled to the sink alone. I was sad for every one of us who must experience such indecency yet glad that I work for a magazine that can tell stories like Ariel's. As a result, one day I hope, Puerto Rico and the world will respond differently, and no person living with HIV will suffer or die from neglect as thousands of people are doing right now on an otherwise beautiful island not far from our shores.

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