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The Lessons I Learned as an AIDS Volunteer

I meant well, but I jumped in without any training. Making a difference meant doing it the right way.

posted by John Stark, April 22, 2013 [More by this author](#)



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When I heard that St. Clare's Hospital in New York was in desperate need of volunteers to help AIDS patients, I decided to sign up. I went to the hospital, which was then located in New York's Hell's Kitchen, one evening after work. I met with a thin, silver-haired woman who was in charge of the volunteer program. She looked very Upper East Side. Proper, but also flustered and overworked.

It was the spring of 1986. The AIDS epidemic was rampant in

New York City. At the time, there was no known treatment.

A few months earlier, in November 1985, St. Clare's made news when it became the first dedicated AIDS facility on the East Coast, and only the second in the nation. New York's Cardinal John J. O'Connor, who died in 2000, approved and supported opening a 60-bed unit to care for people who suffered from the disease.

Taking in AIDS patients gave the Roman Catholic hospital a new life. It had declared bankruptcy a few years before.

St. Clare's, which eventually did close, was in a bulky brownstone on West 52nd Street in Hell's Kitchen. It was a short walk from my apartment on West 55th Street and my office at Time Inc.

I was 35 years old at the time and riddled with guilt for not being active in the war against AIDS. I had lived in San Francisco for 15 years before moving to New York in 1984. I knew plenty of people who had died from the disease. I was alive. I was healthy. I needed to get involved. In my own small way, I wanted to make a difference.

But to make that happen, I had some lessons to learn along the way.

Saying Yes, but to What?

Most of the AIDS patients at St. Clare's were young gay men, but there were also men and women who'd gotten the virus from needles. A locked 10-bed ward housed prisoners.

The primary duty for volunteers, I was told by the silver-haired woman, was to push juice carts from room to room. Patients had to be kept hydrated. She asked if I could start right away, meaning now. I said yes.

My training program consisted of accompanying another volunteer on his juice-cart rounds that

first night. After that, I was on my own. (See "The Importance of Being Trained" at the end of this article.)

I found myself going to St. Clare's several evenings a week. I felt needed all right. On some nights no volunteers showed up.

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Upon arriving I would load up my metal cart in the kitchen with large cans of juice, Ensure, pitchers of water, plastic cups and flexible straws. The AIDS patients were on the second and third floors, where ice machines were located near the stairwells. I would fill plastic buckets full of ice to put on my cart. Trouble is, the ice machines didn't always work.

The patients craved ice. They needed it to cool their fevers and soothe their parched throats. Several times a night I would hike a few blocks up Ninth Avenue to the A&P. I would buy bags of ice, as many as I could carry. I'd bring them back and fill the patients' cups with cubes. You'd have thought from their gratitude that I was handing out diamonds.

I complained to the director of volunteers about the barely functioning machines. "We need a lot of things," she told me.

Trying to Comprehend It All

Every night I returned home from St. Clare's trying to process what I had just witnessed: A dead body left for hours on a gurney in front of a broken elevator. A patient with dementia urinating in the hallway. Some patients had so much white thrush in their mouths that they looked like mad dogs. I learned to be careful entering rooms. A few times I had to quietly back out when I'd hear a soothing voice say to a patient, "It's OK to let go now."

I remember a young publicist for the Metropolitan Opera angrily ordering a priest out of his room. I asked him why he did that. "He just told me I had made my bed and now I had to lie in it," he said. The nuns who came to visit patients were full of cheer and positive energy. They never judged anyone. I recall one discreetly looking the other way after a patient offered her a slice of his birthday cake, which was in the shape of a phallus.

Learning From the Mistakes

I once made a batch of macaroni and cheese for a patient who told me he was craving it. He took one bite and spit it out. I had lightly seasoned it with cayenne pepper. "Are you trying to burn out my insides?" he said. Lesson learned: Don't be a chef. Sick people taste food differently.

I had been volunteering at St. Clare's for about five months when I met Fernando, a young Puerto Rican who had purple-colored Kaposi's sarcomas all over his body. For two days he had been in a coma, but had pulled through. His spirits were remarkably good. "I was voted Mr. Fire Island last summer," he told me. "I'm in a calendar. I'm lying on the beach."

Fernando's health rallied so much that after two weeks he was told he had to leave St. Clare's. Beds were scarce. "I have nowhere to go," he told me. "I have no family here. My boyfriend won't let me come back."

I was taking a short trip to California the following week. "You could stay at my place while I'm gone," I foolishly blurted out.

Arrangements were made. I gave Fernando the keys to my studio apartment. He agreed not go into the hallway or do his laundry in the basement without covering up his unsightly lesions.

When I came back a week later, I was met in the lobby by the super: "You have to get your guest out of here," he said. Fernando had violated the cover-up rule. He had been parading around the building in a tank top and shorts. The residents were freaking out.

I went upstairs and confronted him. "It's their problem, not mine," he said.

He began screaming at me when I told him he had to leave right away. I finally had to call the police to remove him.

(MORE: Can We Get Some Volunteers, Please?)

I phoned the silver-haired lady who was in charge of volunteers to tell her what had happened. “I can’t believe you invited a patient into your home,” she said. “How could you let yourself be manipulated like that?”

She was right. I should have been savvier. But maybe if I had been given some guidelines for dealing with the terminally ill I might not have made that mistake. I meant well.

In the end the incident made me a better volunteer. From then on, I set boundaries. No cooking meals, no giving out my keys. I kept my personal life separate from my volunteer one.

A Surprise Visitor

One hot hot summer night I decided to drop by the hospital with bags of ice for the patients. It was late, but I knew they were probably having difficulty sleeping. St. Clare’s had no air conditioning.

I walked into a room with my juice cart and encountered Cardinal O’Connor at a patient’s bedside. Rumor had it that he sometimes dropped by the hospital when he thought no one would see him.

He was a pariah in the gay community because of his outspoken criticism of homosexuality. He publicly opposed state and city legislation banning discrimination against gays. He supported the decision by the Ancient Order of Hibernians to exclude the Irish Lesbian and Gay Organization from marching in New York’s St. Patrick’s Day Parade.

He asked if he could accompany me on my rounds. “What is it the patients need most?” he wanted to know as we proceeded down the fluorescent-lit, linoleum hallway. “Ice,” I told him. “They want ice. They can’t get enough. The ice machines here rarely work.”

When I arrived at the hospital a few nights later I was shocked to discover that the old ice machines on both the second and third floors had been hauled away. In their place were shiny, brand new ones.

Had a miracle occurred?

The next day I asked the director of volunteers where they had come from.

“McDonald’s Corporation donated them,” she said. “We didn’t even ask for them. They just showed up out of the blue.”

That was the day I learned the most important lesson about being a volunteer: You really can make a difference.

Sidebar: The Importance of Being Trained

It’s easy to say, “Hey, I think I’ll be a volunteer.” But being one isn’t always so simple. To be an effective one, you need to be prepared. My experience helping terminally ill patients at New York’s St. Clare’s Hospital presented me with some scenarios that I wasn’t able to handle well. I spoke with Marci Alboher, vice president of Encore.org, and author of *The Encore Handbook*, about the need for training. If you’re thinking of volunteering for an organization, here are some of her tips. You’ll find more in her book.

- The first thing to do is see if they have any training for volunteers. Who is in charge of volunteers?
- Does the volunteer program have a way of bringing volunteers on board that shows some thought has been given to it?
- One of the best things I’ve heard is when an organization tells someone who is interested in helping, “I’m sorry, but we don’t know how we’d make good use of someone like you.” It shows they’ve given thought to the process.
- Know what you can handle. I’m not so sure I’m so good in personal care situations. So I would

never volunteer to be in a hospital interfacing with patients.

- The best thing you can do is to find people you know who have done volunteer work for the organization you're interested in. Ask them about their experiences.

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