The House That Love Built

Joseph's House was founded in 1990 as a refuge for homeless men with HIV. Today it is one of the many places across the United States where people with AIDS end their days. A poignant look inside this Washington, DC, hospice--and the healing it provides.

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When DeAngela was diagnosed with AIDS in 2011 she had lost a lot of weight and could hardly walk. So her doctor suggested she go to Joseph's House, a Washington, DC, hospice for people with late-stage HIV/AIDS and other life-threatening conditions. But she wasn't ready to live in a hospice—not yet. She opted instead to go to the emergency room where she was stabilized enough to be discharged and sent home.

But the problem with home was that no one was there to tend to her pain, to cook for her or help her to the bathroom when she needed assistance. Her mother and aunt had passed away in 2010. "Those two women gave me everything," DeAngela, 53, said in a crackly, peaceful voice that drags her words along sorrowfully. "I shut down after [they died]," she added. Her mother and aunt were the only ones who knew about her HIV diagnosis; many of her other family members weren't educated about HIV, even though she'd lost a sister to the virus.

Alone in her apartment, DeAngela's health eventually deteriorated again. This time the ER doctors said that her kidneys were at risk of shutting down. She knew she was in bad shape. But when two nurses from Joseph's House, Ann and Priscilla, invited her to come live at their facility, DeAngela still said she preferred to fend for herself. "I was always head-strong," she explained. "I always did what I wanted to do."

The third time DeAngela was admitted to the emergency room she was unconscious for three days. When she awoke, she was scared. She didn't want to die alone at the hospital, so this time she accepted the nurses' invitation.

"I was apprehensive because I kept hearing how nice the people were." DeAngela had been inside nursing homes before and had seen how people were mistreated. Her street sense was telling her: If it sounds too good to be true, it usually is.

In August of 2011, DeAngela was admitted to Joseph's House, and now she has a different view. Sitting in an armchair in the living room, she told me her story while watching *The Fugitive* on the nearby television. "They tried to describe what was here for me, but I had to see for myself," DeAngela said.

The gray-brick, corner row house that is Joseph's House doesn't look like much from the outside; it's not nicer or shabbier than the other houses on its block in Northwest Washington. But as you climb the steps, cross the terrace and walk through the door, you get the sense that you've entered a special kind of place. What makes the hospice unique is not only the high level of medical care provided for the seven to eight people it houses at a time (about 40 per year). It is also extraordinary because it is run like a family home. That sense of family can be traced back to its beginnings.

Patricia Wudel, the nonprofit's executive director, recalls her first encounter with Joseph's House in 1990. After a Sunday prayer service she struck up a conversation with Ron, a young, good-looking African-American man, over doughnuts and coffee. After talking, he invited her to meet his family and walked her to Joseph's House, where he lived.

"He opened the door and the aroma of ham and eggs and coffee swept us into the dining room," she told me. Though packed with people, space was cleared for the two newcomers.

"I was working at an international agency, and I had never experienced black folks and white folks laughing and enjoying each other's company the way that they were at this table," she recalled. Over the course of the meal she saw an intimate moment between two men: One man was in a wheelchair, very thin and weak, while the man beside him was feeding him.

"I noticed how at ease they were with each other. It was a small thing but such a big thing." After breakfast was over, Ron turned to her and said, "I don't know if you know where you are, but this place is called Joseph's House, and it's a home for men who are homeless and have AIDS, and I live here."

Suddenly, everything clicked. "I knew I wanted to be part of that belonging that Ron felt and that had been extended to me at the table," Wudel said. So she kept coming back, eventually becoming part of the house's staff.

Alongside the home-cooked meals and camaraderie served at Joseph's House, there is also the incomprehensible task of facing impending death. Residents sometimes undergo hellish symptoms before passing. "I often get a sense of a person running a marathon," Wudel said of her experiences bearing witness to a resident's last moments—but then she told me about a man who slipped out of his body so silkily and beautifully, with no trouble.

For the house's volunteers and staff, an essential part of their job is to help ease a person's transition to death through support and compassion. Along the way, relationships of profound complexity are forged, as caregivers and residents will often open their hearts to one another. During my visit I saw how the accumulation of many small moments amasses into something that can be roughly identified as love. One moment unfolded in front of me in a large, spacious room shared by two residents on the second floor.

"I get this feeling sometimes that I don't belong here," said Cecil, a bed-bound resident who was looking through his thin-rimmed glasses at a well-built volunteer with a bushy beard and Boy Scout good looks. The volunteer, Kevin, sat comfortably and attentively at the edge of Cecil's bed.

"Is this where I'm supposed to be?" Cecil asked. It had been a bad day, worse than most, and he had spent most of the afternoon enduring a tormented sleep, or pretending to be asleep because he didn't want the house's staff to bother him.

He explained his withdrawn silence, telling Kevin: “There are times when you just don’t want to talk to people.”

“You wanted to be alone,” I added, inserting myself into the conversation. “That’s right,” Cecil answered, trying to suppress an uncontrolled smile. Then his thin frame bounced with a slight chuckle, anticipating what he was going to say next. “But I don’t want to discourage you [from approaching me], because of all the times I *do* want to talk.”

I understood Cecil’s honest confession of not wanting to be bothered. Wouldn’t I feel the same way were I in his position? On some level, I understood his fears and anxieties.

Sitting at Cecil’s side, I suddenly realized that I’d spent the majority of my visit to Joseph’s House with the residents who were doing relatively well. I’d avoided the rooms of the two men dying of AIDS. But before discussing why I subconsciously avoided the dying men, let me first go back to the house’s origins.

David Hilfiker, the founder of Joseph’s House, was a DC-based physician working for Christ House, a clinic for the homeless, when the AIDS epidemic hit in the late 1980s. Hilfiker lived above the facility with his family as well as a few of his coworkers. The staff became increasingly concerned when the men they were seeing began dying of AIDS in great numbers. The men’s final days were often spent shuffling between hospital emergency rooms and the back alleys where they lived. At the time, homeless shelters refused to accept people who were sick and nursing homes refused to care for people with HIV/AIDS.

It was plain to Hilfiker that Christ House was unprepared to provide care for people who were dying—it was a temporary care facility. He did what he could, but the men were getting sicker and sicker, and they needed somewhere to go besides the street. In the midst of wondering what to do, one of his coworkers came across a large row house with a “For Sale” sign out front while walking her dog. At Hilfiker’s prompting, Christ House’s executives eventually agreed to purchase the house. A short time later, Hilfiker and his family moved in along with three of his homeless clients.

From the beginning, Hilfiker established the foundations of mutual respect and compassion between resident and caregiver. The house only has three rules: (1) No drugs or alcohol. (2) No violence. (3) Residents must attend community meetings twice a week. Hilfiker soon realized that he could learn much more about the residents by spending his days with them rather than during scheduled office visits. When he treated them with respect and compassion, they grew to respect him, too. Hilfiker and his staff created a home, in the true sense of the word. Residents, staff and Hilfiker’s family shared meals together, laughed together and mourned together when a member of the house died.

Today, Joseph’s House is not so different from the home that Wudel walked into on that distant Sunday morning or the home that Hilfiker first built. One major change is that now both men and women fill the spaces in the house. Another difference is that even though the majority of residents are HIV positive, after protease inhibitors became available in 1995, Joseph’s House extended its mission to also cover other terminal illnesses. But despite these changes, the soul of the house remains the same. And the staff still prioritizes helping people with no financial or family support.

“I just fell in love with everybody here,” DeAngela said, continuing her story. I’d observed her embracing some of the volunteers with unbridled affection and saw that the love went both ways.

“I was amazed at the lack of censorship, the kindness, the loving atmosphere and the [quality of] care,” DeAngela said. “They fed me and fattened me up,” she added. “It was just wonderful.”

When DeAngela arrived she was so weak that she had to be carried into Joseph’s House. She wasn’t able to take her HIV meds because she couldn’t swallow them and would vomit every time she tried. Most of her time was spent curled up in a little ball on her bed, not able to eat much of anything.

DeAngela was slowly nursed back to health. She still has bad days, but she’s now able to walk on her own and draws satisfaction from being able to do her own laundry. She’s scheduled to leave the house in springtime and go live with a sister in Raleigh, North Carolina.

“I know a lot of people who come here thinking they’re going to die—and a lot of times that is the case—but not in all cases,” she said. “I seem to be getting better, and my numbers have improved,” she told me, referring to her CD4 and viral load counts.

Inevitably, not everyone at Joseph’s House gets better. People still die of AIDS there, largely because by the time some are admitted, the disease has progressed to an irreversible state. Others have become resistant to existing treatment options.

On the day I arrived everyone at the breakfast table was aware that we’d be attending a service for two former residents later that day. The service would be held in the living room. An assemblage of candles would be lit for the deceased, and memories would be shared. In between a brief discussion about the service, people offered me eggs and bacon and we launched a debate over the merits of oatmeal versus grits. Death is a natural part of what happens at Joseph’s House. And those living must learn to face it.

Still, nothing really prepares us for death. Though many of us have seen friends and lovers die of AIDS, we are loath to admit that it is still happening. And often we cannot be there to bear witness to the dying, to be there for them, to hold their hands and love them as best we can until the light is gone from their eyes—especially when they’re strangers. Places like Joseph’s House undertake this work for us.

“So much healing cannot happen in a [traditional medical] institution,” Wudel explained to me later. “When it’s a warm and welcoming home, a certain quality of truth or healing can happen,” she said. “It’s not just the people who are dying who seek healing—the friends, the caregivers, the family are, too,” she added. “We’re human—we all hurt.” Wudel’s observations resonated with me and made me realize that while I came to Joseph’s House on a search for truth, I also needed some healing of my own.

“I’m visiting the house to write about what happens here,” I told the people around the breakfast table the day I arrived. I nearly cried as I said it, perhaps under the weight of all the other things I was not telling them. That I have HIV. That my mom died of AIDS. That I’m scared as shit of dying like she did, and that I came here to bear witness to the truth, that AIDS deaths are still happening when they can be prevented. My mother died in 1996 but was already too sick for protease inhibitors to be effective.

David Hilfiker laid out the reason we often cloak our dead in silence. “To see people dying of AIDS means you have to do something about it,” he began. “We all see ourselves as compassionate people—so you either have to not see the dying, or blame them for their position. We do both of those things.” Part of what Hilfiker was implying was that AIDS-related deaths overwhelmingly affect sexual minorities and fall along racial, ethnic and socioeconomic lines—wounds in our country that also need immeasurable healing.

Hilfiker used Washington, DC, to illustrate his point: There are areas where you can enjoy the majesty of the Capitol and the Lincoln Memorial; there are affluent white and African-American neighborhoods; and then there are the inner city areas, where many people live in poverty and the rate of HIV infection rivals that of some sub-Saharan African nations. Americans with AIDS are dying just a metro stop away from the very buildings that house the national leadership that could fund better access to care and save those people's lives.

Reflection on how and why people in the United States still end up in places like Joseph's House reminds us of some basic truths: You can't treat your HIV when you don't have a stable place to live. Or when you are struggling with addiction. You can't treat HIV if you're scared to get tested. And you can't treat HIV if you don't have any money or emotional support.

I didn't have to leave New York City to face the fact that African-American women are more than 20 times likely to die of AIDS than white women. But that uncomfortable truth is only part of what needs to be understood about today's epidemic. We must shed the selective vision that prevents us from responding to the epidemic, the selective vision that makes so many of us blind to people dying of AIDS.

Although I never told Wudel what I realized in Cecil's room—that I was afraid of facing the residents near death—she shared this observation: "It's helplessness that keeps us from entering the room [of someone dying]. It's painful to feel helpless." She was referring to the helplessness that pierces you when you see someone who's grievously sick. When you watch someone lose control of his or her bladder—when you don't feel equipped to respond—it's easy to maintain distance and not enter the room, but even once you go inside it takes practice, self-awareness and patience to be of help to the person you're with.

"Allow yourself some mercy for not being who you want to be with this man, or with this woman," Wudel said. Her wish is that the volunteers and staff spend enough time with each of the residents to see the light inside of them, and vice versa. With time, the boundaries disappear and a greater level of healing can occur. "Love is better than protecting oneself [from unpleasant realities]," Wudel said. "But love has to be practiced."

At Joseph's House love is practiced every day.

Editor's Note: After this issue went to press, POZ learned that Cecil, one of the residents interviewed in this story, passed away. A memorial service was held in the living room of Joseph's House on February 23. His brother, daughter and the house's volunteers and staff attended the service.
