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# Surviving AIDS: The Extraordinary Power of a Helping Hand

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With the news of Broadway composer [Michael Friedman's](#) recent death from HIV/AIDS, we have an opportunity—if not a responsibility—to heighten awareness that the scourge of AIDS still exists in America. This week, as we recognize [National HIV/AIDS and Aging Awareness Day](#), it seems imperative that we not let complacency keep us from acknowledging the ever-present dangers of the virus—or the powerful solutions that keep at-risk members of our communities from sinking into the abyss.

For more than a decade, Luis D.\* was keeping his HIV in check, taking his medication and regularly visiting a clinic in his Bronx neighborhood. But two years ago, when he moved to Far Rockaway, Queens, things abruptly changed. There were no more clinic visits, and he stopped refilling his prescriptions. This put the sixty-year-old at risk for serious complications from a disease that has been turned from a frightening killer into a chronic, manageable condition.

Fortunately for Luis, someone noticed that he had fallen out of care—specifically, Dr. Bill LaRock, nurse practitioner and public health clinician, who once worked in Liberia with Ebola patients and in parts of rural South Africa devastated by HIV/AIDS. Today, Bill leads a New York City program for [VNSNY CHOICE](#) Health Plans dedicated to reducing HIV statewide by helping people return to care. This includes Luis, whose viral load is now again undetectable, meaning the condition is under control.

Through [SelectHealth](#), a special-needs plan for people with HIV, VNSNY CHOICE received a grant from New York State's ambitious "[End the Epidemic](#)" initiative, which aims to reduce new HIV infections and improve the health of people living with the illness. The main objective of the three-year grant is to increase the Viral Load Suppression rate by at least 20% in some 650-700 plan members who are no longer in control of their HIV. At the end of 2016, the program had met the goal with 26% of the group virally suppressed.

Breakthroughs in medication and care delivery models have made the treatment of HIV equally or even more manageable than other common chronic illnesses such as diabetes and hypertension. For example, medications, now taken once or twice a day, are much less onerous than the complicated regimen of years ago. "The fact is," says Bill, "people should not be dying of AIDS in New York in 2017. Nobody with HIV should get into a giant abyss they cannot get out of." To make sure this doesn't happen, everyone enrolled in SelectHealth is signed up with a clinic or HIV treatment site, as well as a primary care physician or nurse practitioner.

## *'Walk the Journey'*

So what causes people who have a plan of care in place to stop following it? For Luis, it was a move, which took him to an unfamiliar neighborhood, one where care was more difficult to find than in the Bronx. Isolation and fear of stigma took hold.

The healthcare industry uses the phrase "barriers to care" to describe things that stand in the way of people, particularly those living in poverty, getting to the doctor or fulfilling prescriptions. This can include unstable housing, mental health issues, drug addiction, difficulty navigating the healthcare system. Many of the people Bill works with indeed face these barriers, but, by the same token, they have successfully found care earlier in their lives—which is why he prefers to talk about "priorities."

"Let's face it," he explains. "People who live in extreme poverty are often in survival mode. Navigating the day or the week takes a lot of work. Going to the doctor, which may have been at the top of their list three years ago when they were really sick, has now been bumped down to fifth or seventh."

In some ways, people in this group are a victim of their own improvement: they're feeling better, and so they're opting to deal with more urgent life issues. Once they do this, however, they are putting their health at risk. And that's where the SelectHealth team comes in. "We help them walk the journey back to putting care at the top of the list," says Bill. The team of Peer outreach workers and a nurse practitioner is a unique collaboration with the [Alliance for Positive Change](#) (formerly the AIDS Service Center), a long standing community based organization in New York City.

The team does that in person, rather than leaving a voicemail or sending out a brochure. In fact, for many people who have fallen out of care, things like a working phone number or mailing address are—like much of the rest of their lives—far from stable. So the care team travels neighborhood to neighborhood, walking up flights of stairs and knocking on doors. "Nine times out of ten," says Bill, people welcome them in—and are even happy to usher them into their homes. At the very least, the SelectHealth team member is someone to bridge the isolation that living with HIV can bring, born of stigma or poverty or simply aging, when social circles narrow and mobility grows limited.

In the U.S., HIV is, increasingly, a disease of older people. [Statistics](#) show that 50% of Americans living with the disease are age 50 or older, a proportion expected to rise above 70% by 2020. "All the things that go with aging in general—chronic illness, isolation—piled on top of HIV really compound things," Bill notes. "We didn't think twenty years ago that, being experts in HIV, we were also going to have to become experts in cardiac disease and hypertension. But those skills have become increasingly important as people age with HIV and face these other conditions that often accompany aging."

The feeling of stigma may be felt more acutely in the older LGBT community, who came of age in a time of discrimination and fear, around both their sexual orientation and AIDS at the dawn of the epidemic.

### ***The Power of Peers***

One key to the SelectHealth grant program's success is that peer counselors—people who themselves are living with HIV and have at one time fallen away from care—are the ones who first knock on the door. Hence, no judgment. "They won't wag a finger," Bill says.

For many of the at-risk New Yorkers on our health plans, forming relationships is at the core of connecting them with the health care they need. It is not only about medication, doctor's visits, tests and numbers (although these things are important). It is about, as Bill says, having someone accompany you on the journey. The peer counselors trained by the Alliance, living and thriving with HIV are in a unique position to bridge plan members back to care. The visiting SelectHealth team also includes three peer counselors from the Alliance for Positive Change, a nurse practitioner from [Project Renewal](#), another community based organization, and Bill, who step into the cases as needed, and provide another layer of care and attention.

"Not that we can fix the situation entirely, and not that folks don't bear some responsibility around their choices—such as getting to the doctor and taking their meds," Bill says. "But the idea is that there is someone who will accompany you in your efforts, who can speak to what you describe as your struggles."

He recounts how peer counselors begin the conversation, what they promise and what they don't: "We get that this isn't as simple as it looks," he describes them as saying. "We're here for you. We want to do this with you. We'll even go to the doctor with you, if you want. Then when you don't need us, we're going to go away."

And that's just what the team does. Once the plan member is regularly visiting the clinic and is taking and refilling prescriptions, and once the [viral load and T cell counts](#) are where they should be, the team turns the case back over to the regular workings of the health plan and the oversight of the case manager.

### ***Luis' Success Story***

While HIV clinics were indeed hard to find in his new neighborhood (and his old clinic was nearly a two-hour commute away), the SelectHealth team was able to find Luis a nearby small family clinic that could treat him, and the peer counselor accompanied him to his first visit there. In addition, the team connected Luis—whose high blood pressure and cardiac history put him at risk for heart attack—with a cardiologist. He has since had some stents replaced and sees his cardiologist regularly. "All in all, he's doing great," says Bill.

So is Adolfo\*, a sixty-something plan member in the Bronx who was in a bad way when the program found him: mourning the death of his wife, who had kept him on the straight and narrow when it came to his health. Since her death, suffering from depression, he lost fifty pounds, relapsed into drug addiction, and stopped taking his HIV medication or visiting the clinic. He lived with his mother, who was desperately worried about him.

The visiting nurse practitioner, like something out of *A Christmas Carol*, laid out two distinct future scenarios, one of an increasing toll on the body, mind and spirit, and another of improving health and repaired relationships. "This is what it could look like if we don't get you hooked up with care," Bill recounts his colleague as saying. "And this is what it could look like if we do."

The brighter scenario won out. Adolfo went back to the clinic, got back on medication, and connected with mental health care. "He's doing great," says Bill. "His mother has told us that we saved his life."

\*Names changed to protect privacy