Staying in Care

Keeping doctor's appointments isn't always easy, but it's key to HIV wellness. Some providers want to help.

December 1, 2009 By Tim Murphy

Two years ago, things weren't going too well for Brooklyn's Eric German, 40. Diagnosed with HIV in 1991, he'd lost his bartender job, was stuck living with a physically abusive boyfriend, was drinking too much—and was starting to miss doses of his HIV meds as well as appointments at his HIV clinic. "I wasn't really happy with myself," he recalls. "I was down and depressed a lot."

So his doctor at St. Vincent's Comprehensive HIV Center in Manhattan referred him to the hospital's special Maintenance and Care program. Launched two and a half years ago, the program oversees about 4,000 HIV-positive people (and is one of a handful of such programs in New York funded by the city's health department). The plan: to find patients who, for various reasons, have stopped showing up for appointments, get them back into care and keep them there. Staff workers make repeated phone calls and, when necessary, home visits; they also offer ample hand-holding and moral support when patients come back around. "Our motto is 'Never give up,'" says Antonio Urbina, MD, the program's head and St. Vincent's director of HIV education and training. Persistence counts: Studies have shown that people who regularly have their labs done and make doctor visits control their HIV and general health better than those who drop out.

Urbina's team includes nurse Daisy Soto, who makes all those calls, and outreach worker Edwin Ortiz, who canvasses the city daily knocking on the doors of those who haven't shown up for three months or more. People disappear from care for a variety of reasons, from lacking subway fare to having kids to take care of, to suffering emotional problems. "The two major reasons are substance use and mental illness," Soto says. "So Edwin goes into their homes. We're very successful at getting our patients back into detox or a short- or long-term drug-treatment program."

They're also successful at getting patients back into HIV care: Urbina says that of 200 patients the program reached out to in its first year or so, it brought 95 percent back into regular visits. The team also connects people to social workers who help them sort out Medicaid and ADAP coverage, get transportation to appointments and secure child care, if they need it.

"It takes a lot of choreography" to get some people back into the clinic, Urbina says. In one instance, Ortiz had to visit a woman five or six times at her home in outer Queens before she

finally allowed him to escort her to the clinic, then into treatment for her cocaine addiction and pregnancy—but the team pulled it off. It's not usually that hard—more often, Ortiz says, "People are like, 'Wow, St. Vincent's sent you to visit me? That's so wonderful!'"

Realizing that such efforts can dramatically improve rates of people staying in care, the Centers for Disease Control (CDC) recently began a five-year study at six large HIV clinics around the country, randomizing patients into three groups. One group will get whatever support the clinic is already offering to keep people in care; another will get a few basic messages and phone calls about the importance of showing up for clinic visits and labs; the third will get intensive help trying to remove the barriers—domestic issues, substance use—that keep people out of care. It's too early to tell, says the CDC's Lytt Gardner, PhD, but if the study shows that beefed-up intervention keeps people in care, federal health officials will likely write those interventions into their HIV-care guidelines. Right now, Gardner says, data show that up to 40 percent of HIV patients miss at least two visits a year—not good, considering that four visits a year (one each quarter) is the general rule of thumb for HIV-positive people—no matter what their viral load is.

Miami's Jackson Memorial Hospital, with about 3,000 HIV patients, is one of the CDC study sites. The hospital's Allan Rodriguez, MD, says the first steps have already produced an 8 percent rise in visits, though he adds that it's too early to attribute that solely to the new program. The clinic already has two outreach workers who make home calls.

As for German, he didn't need a home visit. A phone call from Soto was enough to get him back to the clinic and opening up to her about his abusive relationship (she urged him to get his own place, which he did, with public assistance), his drinking (she got him into a harm-reduction study, and now German hasn't had a drink in five months) and his depression (the program helped him get in to see a shrink). Wearing funky glasses and a silver cross his mother recently gave him, German looks great now. He's moving out of temporary housing and into his own apartment; he's interning to become an HIV peer educator; and he has been seeing someone new for four months. "He's a lot more outgoing," Soto says. "He seems happy."

A big part of his new attitude, German says, comes from Soto's continued follow-up. "She'll call me two days before an appointment, the day before and the day of, to make sure I show up." Soto laughs. "I can show you in the records how often I call him!"

KEEP YOURSELF IN CARE
How to avoid missing doses and appointments.

GET ORGANIZED.
Most cell phones have alarms you can set to remind you to take meds and get to appointments. Or use a paper calendar or notebook to record appointments, mark off day and nighttime doses and keep info about meds, clinic contacts, etc. (Mark Rabiner, MD, an HIV doc who works with homeless people in New York City, suggests keeping a small version of this info sheet in your purse or wallet.)

SORT YOUR PILLS.
It’s easier to remember doses if you sort pills once a week, using a container that divvies up day and nighttime doses. You’ll avoid having to sort them when you’re tired, and you won’t forget whether you’ve taken a dose.

FIND MOTIVATION.
This will keep you on track with all those doses and clinic visits. “You want to be alive for something good,” says Allan Rodriguez, MD, of Miami’s Jackson Memorial Hospital. Eric German says he gets his mojo from his mom and nieces. List things that bring you joy and post it by your meds to remind you why you’re swallowing them. If nothing’s raising your spirits, talk to someone—you might be depressed. You can get help for that, too.

REACH OUT FOR HELP.
If you’re feeling hopeless or overwhelmed by life, don’t be afraid or ashamed to call your doctor, clinic, AIDS organization, family or friends to ask for help. Many offices have case managers and social workers so you don’t have to pull off these visits alone. And, Rodriguez says, “if you don’t think you’re being treated fairly [by caregivers], you have the right to change.” So speak up!

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