SENTENCED TO LIFE

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anymore. So what has happened at Chris Brownlie House, and similarly at Boston's Mission Hill hospice, seems almost like the happy ending of a movie. It calls up images from the end of the film *Longtime Companion*, when the clock turns back to a time before we knew so much sickness and grief.

Except, of course, we are not at the end of the movie. AIDS service organizations, hospital wards and even hospices are still unfortunately necessary and will probably be so for years to come. But there is no question that treatment advances have shifted the paradigm of what it means to serve the HIV/AIDS community.

Even before the introduction of protease inhibitors as a treatment for HIV, AIDS service organizations that were originally set up to offer what comfort and help they could to the dying were adapting to serve people for whom AIDS had become a chronic, long-term disease. But the hope offered by protease inhibitors has clearly accelerated that process.

For example, due to the increasing demand, the AIDS Healthcare Foundation started making plans three years ago to build a new hospice. It opened just five months before Chris Brownlie House closed. Meanwhile, because the foundation provides services without regard to the ability to pay, it has been swamped by the costs of providing protease inhibitors—so swamped that it entered into a partnership with a medical group operated by AIDS pioneer Dr. Michael Gottlieb in order to cut costs enough to keep all of its clinics open.

"It's a strain, but it's a strain that I welcome," says Kenslea. "It's good bad news. But the bigger picture is that this is forward moving."

In Texas, AIDS Services of Austin traditionally provided clents with long-term case managers who would see and support them through to the end. "The more dependent someone is because of their deteriorating health, the more they want the physical and emotional support of a case manager," explains Peter Brownlie (no relation to Chris), the agency's executive director.

Now, though, people whose health has improved because of new treatments can be more independent, Brownlie says. And because they feel better, many of them don't need the same level of emotional support. So at AIDS Services of Austin, resources are being shifted away from long-term case management and toward providing information and short-term support—handling questions about going back to work, problems with Social Security, getting into programs to pay for drugs, etc.

Brownlie says his organization is also renewing emphasis on its prevention message because of the fear that the media attention about the new treatments may make some people less vigilant about safer sex. He also expects that his clientele will continue to shift, as it has been doing in recent years, away from predominantly white gay men and toward heterosexual people of color, especially women, and drug users. These often less-advantaged groups may have less to gain from protease inhibitors, due to the cost of the drugs and the complexity of their use.

"We will need to continue to diversify our staff and diversify our programs," he says.

And in the long term, "I think we will become smaller. I think the need for what we do will decrease," Brownlie says. "And that's fine. We've always said that what we wanted was for there to no longer be a need for what we do."

And yet, that creates a dilemma for people who work in AIDS service organizations. Many abandoned other careers to dedicate themselves to helping with the AIDS fight, often inspired by their own personal losses. But if protease inhibitors succeed in turning AIDS into a chronic manageable disease, those miracle drugs may put many of these dedicated people out of work—particularly in agencies that provide end-stage services, such as hospices, and groups that provide meals to shut-ins.

"As happy as they may be, in a practical way, they are wondering what they will do next," says Mark King of AID Atlanta, a former actor who spent the past decade working as an HIV/AIDS educator in Atlanta and Los Angeles after testing positive in 1986. "That's only natural. Many of them have spent much of their professional life doing this."

If all of the recent hope and hype have generated uneasiness in AIDS service workers, they have also generated an uneasy, nagging question for those who lead these groups: How will all of this affect fund raising?

The creation, from scratch, of a support network for people living with AIDS in the face of government indifference stands as one of our community's most remarkable achievements. But as these organizations, driven by unfortunate necessity, have grown over the years, so too have their fund-raising requirements. Anything that affects the public's perceptions about AIDS, then, has the potential for remarkable affect on their ability to raise the voracious amounts of money they need.

"I think there are people out there who have identified protease inhibitors as a cure, and there is a sense that may decrease the sense of urgency about donating," says Austin's Brownlie. "But it hasn't had an impact on us yet."

Like the fears about a surge in risky sex because of the mistaken perception of HIV as curable, the thesis that fund raising may be endangered also remains unproven at this point, with only isolated anecdotal evidence. Many echo the analysis of Thom Weyand, development director at the NAMES Project Foundation, who says, "I acknowledge that is probably happening, but we haven't experienced it to date as far as I can tell." Weyand also says other factors, including the fact that the AIDS fight has now stretched 15 years, could account for some reports of fund-raising difficulties.

"But certainly, it is logical to think that perception can have a negative effect when it comes to trying to raise money," says Jeff Monford of the National AIDS Fund in Washington, D.C. "We are anticipating that could happen."

Because of the access problems related to protease inhibitors, gay America, which has been the backbone of AIDS fund-raising, will probably benefit more from this breakthrough than those in other marginalized communities who have entered the AIDS nightmare after us. So if creating and funding the AIDS service network in the beginning was a challenge that the gay community met, then the next test of character may be whether we continue to provide the same level of support to these service providers, even if their focus shifts away from predominantly white gay men with HIV/AIDS to those in potentially greater peril.

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Part 5: Mixed Emotions

AIDS has been a war: ugly and harsh and brutal and numbing. Comrades have died. The enemy has been cunning and unceasing. Death has obscured hope, dashed dreams, exiled the future.

And when a war is over—or when perhaps the enemy just seems to be in retreat—there is not always, or only, euphoria. Some soldiers came back from Vietnam ill equipped to cope with their new reality, unable to sleep, keep a job, sustain a relationship. They checked for snipers on every rooftop. They had seen too much—lived life too long on the edge of death—to go back to where they were before the war.

On a January night, a room full of survivors of the AIDS fight sat and listened as Atlanta psychologist Mike Sayer outlined his "war" hypothesis. He told them he was finding evidence of post-traumatic stress in his patients who were getting better because of treatment with protease inhibitors. No one raised their hand or their voice to contradict him. One by one, they confirmed his hypothesis as they outlined the problems and pressures and frustrations they now face as they renegotiate their lives.

In describing the uncertainty his lover was going through, one man made this statement—one that might seem, at first blush, astounding. But in this room, no one was astounded.

"Getting better," he said, "is not always a better thing."

On this night, no one stood up to say they didn't welcome the promise offered by protease inhibitors, that they preferred death. But death, even when it is not welcomed, is final, exact. Once it is accepted, plans can be made, affairs put in order, good-byes said. Life, on the other hand, can be messy, unpredictable. So perhaps it is not quite so astounding that some of those who came to accept being sentenced to death and now find themselves possibly sentenced to life are not just skipping merrily along, humming a carefree, happy tune. All across the country, support groups that once comforted the dying are now switching gears to offer support to the living.

This reaction among some of those most directly affected stands in sharp contrast to the emotional chord struck among those on the outside looking in. For those who are still HIV negative, the sword of Damocles may seem a little further from their neck; family members and friends of the afflicted may also feel less wrought ("This makes it easier for them," grumbled one man at the Atlanta forum). And the mainstream media has been positively giddy—*Newsweek* wove its cover story on this subject around a long-term survivor now competing in triathlons.

"There are some people like that. But for most people, this all seems really scary," says Jon Argenziano, who helps lead a support group for long-term survivors at the AIDS Action Committee in Boston. "You see this sort of guarded euphoria. People feel better, but it is almost like they are waiting for the anvil to drop on their head."

Argenziano says the emotions he's seen among those whose lives have improved on protease inhibitors run the gamut, with uncertainties and frustrations about going back to work, their financial future, and whether these treatments will actually continue to work in the long term topping the list.

"I think what they're really asking in all of this is, 'What is going to become of me?' " he says. Argenziano also relates how another client in Boston reacted with outright anger.

"He said, 'How much more of this can I go through?' He feels totally alienated. He thinks he has to reinvent himself again," says Argenziano.

Jim Thurman, a long-term survivor who publishes a newsletter for people living with HIV in Texas called "Positive Threads," also sees a cautious sort of hope coming from those who have been feeling better. He also says practical worries about the future are driving a lot of the feelings of uncertainty. But he doesn't believe stresses associated with this new reality are driving these mixed emotions.

"I don't think this provides any more stress than was already there," Thurman says. "We've become good at dealing with stress."

Thurman has also experienced firsthand another emotional component, one raised by all of the hope and hype about protease inhibitors—a sense of guilt. For while he has responded to the treatment, it hasn't been effective for a close friend of his.

"I felt some survivor's guilt because it worked for me and it didn't work for him," Thurman said. "But then I thought, 'I might be in that boat someday, too.' What I've done personally is taken the attitude of not worrying about what I can't control."

"It can be really emotionally devastating for people who go on protease inhibitors and don't see the same effects they see in their friends, or for whom the side effects are so intense that they can't continue," says Peter Brownlie, executive director of AIDS Services of Austin in Texas. "They ask themselves all over again, 'Why me?' "

During the 15 years of the war, those living with HIV were encouraged to empower themselves with information. The message was not to trust blindly medical science or doctors but to participate fully in treatment decisions, based on independent knowledge.

What increases the level of frustration that some people are feeling with protease inhibitors is the fact that there is little long-term data available to empower people. These drugs were approved by the Food and Drug Administration under an accelerated process, which means that even doctors aren't sure how long this new-found health might last. Many people feel as if they are making decisions blindly, which increases their anxiety.

In addition, as in Vietnam, the war itself changed the warriors more dramatically than it did the outside world, making reintegration a difficult task.

Among the observations tossed out in the session with Sayer was that society is ordered in this fashion—you're born, grow up, are educated, establish yourself in a career and a relationship, and then accumulate the wherewithal for the golden years. Under this scenario, the process of life is a means to an end.

Even many gay people not living with HIV have eschewed that model, of course. But those directly in the line of fire came to particularly understand that the process of life was important for its own sake—friends, experiences, happiness. For there were to be no golden years.

Perhaps, in the long run, protease inhibitors may give people living with HIV a longer biological existence. But even then, they will have to spend the rest of that biological existence inside a society where so many facets of day-to-day life revolve around a model that they do not—possibly cannot—fit.

"The thing you want more than anything else," said one man at the Atlanta gathering, "is to get back to your normal life. And that isn't happening."