

# SENTENCED TO LIFE

Lanoux's situation is not unique. For people whose health has improved because of protease inhibitor treatment, the decision as to whether to go back to work opens up a whole Pandora's box: How will additional income affect my disability payments, medical coverage and other benefits I am receiving? Overall, how much money will I have to make to receive the same benefits I do on disability? If I'm feeling better but decide I'm not ready to go back to work, can I lose my benefits anyway? If I go on my new employer's medical insurance, will there be a "gap" in benefits? During the interview process, how will I explain not having worked for the past few years without opening myself up to HIV-related discrimination? Disability status protects me from past bad debt, so how will working change that?

HIV advocates who have been investigating those questions have one overriding recommendation for people considering going back to work: Don't rush into anything. Sit down and carefully examine all of the ramifications (with a case manager, lawyer or accountant, if you have them) because you may not be able to undo some things once you've done them.

"You don't want any nasty surprises," says James Grayer, an attorney with the AIDS Legal Project in Atlanta, who has put together a "laundry list" of items that could be affected by returning to work, from veterans benefits to food stamps to life insurance to aid for individuals provided under the Ryan White CARE Act.

Everybody's situation is, of course, unique, and should be individually evaluated. But there are some broad guidelines people should keep in mind before taking the plunge back into work:

- People who are receiving benefits from private long-term disability programs, rather than the government, need to be particularly careful because every policy has different provisions.

A typical private disability policy likely limits how much income can be earned before benefits cease. And unlike government disability programs, private policies may not allow for resumption of payments if a person finds that they are again too ill to work.

Most policies also allow for periodic reviews of disabled status, which could, depending on the policy, allow disability benefits to be withdrawn if the determination is made that a person responding well to protease inhibitors is now healthy enough to work. How often those reviews are made, and the criteria used to evaluate a person's suitability for work, depend on the policy.

- The two federally run disability programs, SSI (the lower-income program that Lanoux is on) and SSDI (for people who had more income prior to becoming disabled) also require periodic reviews of disabled status. As protease inhibitors have started offering the promise (still far from proven) of HIV disease as a manageable, nondebilitating condition, fears have arisen that the Social Security Administration, which administers both programs, might start reviewing cases and forcing some people with HIV who have improved off of the disability rolls.

"Those rumors are circulating. But we've been assured by the folks at Social Security that this is not what they're considering," says Jeff Monford, resource manager for the National AIDS Fund, which has been meeting with Social Security representatives as part of an ongoing study of back-to-work issues.

Attempts to get an official response from Social Security were unsuccessful. But the agency's track record does buttress the assessment that it won't try to push people off of disability.

In the early years of the epidemic, an AIDS diagnosis (based on T-cell count and incidence of certain opportunistic infections) was considered de facto disability. It didn't matter that someone might still be well enough to work. But

Social Security later added a new requirement that, in addition to an AIDS diagnosis, a person be impaired to the point where their daily living activities were impacted. However, the agency did not go back to specifically review cases of people who were declared disabled under the weaker definition, Monford says.

- When it comes to going back to work, there are some stark differences for people on SSDI and those on SSI.

On SSDI, people can work for up to nine months within any five-year period, called a "trial work period," without losing any money out of their check—no matter how much money they make. Those nine months don't have to be consecutive, and they don't count as a "service month" if a person makes less than \$200 during the month.

After those nine months are up, and after a three-month grace period, SSDI recipients won't get payments in months where their income is more than \$500. They will still get a check in months where their income is less than \$500. This protection lasts three years, during which they continue to receive Medicare coverage.

There is a loophole here that can be of particular benefit to people on protease inhibitors. Because these drugs are necessary to be healthy enough to work, the Social Security Administration allows their cost to be deducted from that \$500 threshold. In other words, if a course of protease cocktail treatment is costing a person \$1,200 a month, he or she could make up to \$1,699 a month and still get their SSDI check. And because Medicare does not generally pay for protease therapy, working might be an additional way for people on SSDI to gain access to the drugs.

Boiled down, if people on SSDI go back to work, they will still receive their disability checks for at least nine months and will keep Medicaid for 39 months. During that time, if they get sick again and can't work, they can requalify for SSDI without a waiting period.

For people on SSI who decide to go back to work, however, the situation is much cloudier.

There is no trial work period in the SSI program. Benefits are reduced from the first month, roughly by about 50 cents for every dollar earned. (As in SSDI, costs of work-related treatments, such as protease inhibitors, can be deducted, but people on SSI whose drugs are paid for by Medicaid usually incur only the costs of a small co-payment.) Make more than \$1,025 a month—\$12,300 a year—and SSI payments cease (this threshold may be higher in states that add their own funds to the federal benefit). If payments stop for more than 12 months, then SSI recipients who become too sick to work would have to endure the whole application process again.

Potentially more problematic is what losing

SSI payments may do to Medicaid coverage. Unlike Medicare, which is a uniform federal program, Medicaid is administered by the states, which means there are 50 different sets of rules. The party line out of Social Security is that losing Medicaid is not automatic if SSI payments stop. However, states have different income thresholds for Medicaid, above which the coverage is cut off.

Even with too much income, an SSI recipient might be able to keep Medicaid if the person can prove that he or she needs it to work and can't afford similar coverage on his or her own. But that would require a case review by Social Security to determine if the person is still disabled.

- For people who do decide to go back to work, the federal health care reform law passed last year could help them get on their new employer's insurance coverage.

Under this law, the period of time a person was covered under previous private insurance, Medicare, Medicaid or COBRA (the insurance extension plan a worker receives when leaving her or his job) after June 1996 can go toward qualifying for pre-existing conditions. In other words, if a new employer's medical policy doesn't cover expenses resulting from a pre-existing HIV diagnosis for a period of time (now limited to no more than one year), the period for which a person has been previously insured counts ticks off that clock, unless there has been more than a two-month break where there was no medical coverage of any kind.

A few caveats: Only time spent under insurance coverage

after June 1996 counts toward meeting the pre-existing condition requirement. Also, this law is being phased in gradually and will not apply to all employers fully until 1998. Some small employers may also be exempt.

- Under the Americans with Disabilities Act, potential employers cannot refuse to hire people because of disabilities, including HIV. But for those who have been out of the work force on disability, keeping that information private may be tough because employers will naturally be curious about any long-term gaps in an applicant's work history. And they can ask about those gaps.

"You don't want to lie, because that could come back to haunt you," says AIDS Legal Project's Grayer. "But they cannot ask you to disclose your HIV status."

(At a recent forum on workplace issues at which Grayer spoke, people in the audience tossed out suggestions on how to deal with this problem—applicants could say they were on a "sabbatical" or doing "consulting" or "freelance work.")

Under the ADA, if an applicant does decide to disclose his or her HIV status, that information must be kept confidential. Employers must also make reasonable accommodations to disabled workers, including allowing them to struc-

ture their work schedule in light of the requirements of their protease inhibitor drug regimen.

- People on disability who have credit card or other debts that they can't pay are protected from action by creditors, who generally aren't allowed to garnish disability payments. However, if these people go back to work, creditors can go after any income above minimum wage. So people with a lot of debt may not end up better off financially by going back to work.

- And, of course, the biggest caution when considering whether to return to work is that no one knows for sure how long protease inhibitors might render someone able to function in the workplace. Decisions made now, in the glowing optimism of better health, could turn into regrets down the road.

Lanoux's experience illustrates the need for caution. His health has improved on Crixivan—but he only got Crixivan after failing to respond to the two other protease inhibitors now on the market. He has, for the time being, decided not to go back to work, choosing instead to continue his volunteer work at an AIDS agency.

But he's uneasy about how long he might be in limbo.

"Before, we knew what the inevitable was," he says. "And now, the inevitable is undefined."

## Part 4: "It's Good Bad News"

Perched atop a hill, surrounded by peaceful green space that stands in sharp relief to the nearby bustle of downtown Los Angeles, the Chris Brownlie House was a place for people with AIDS to live, and it was a place for them to die.

Like numerous other AIDS service organizations around the country, the AIDS Healthcare Foundation, which was started in 1987 by a handful of friends deeply affected by the disease, saw the acute need for "end stage" care facilities in Los Angeles. Those friends drummed up enough money and support to turn the former nurses' dormitory into a 25-bed hospice, which opened in 1988. Over the years, it provided shelter to about 1,800 people, including its namesake, Brownlie, a poet and activist whose poem "AIDS" captured the spirit of what these service organizations were striving to do in gay communities all over the country:

*It is the fighting back. It is the building of places to care for the living and the dying. It is courage, it is honor, it is integrity. It is people joining forces in a time of great need. It is hope, it is sharing the burden...*

Last September, though, Chris Brownlie House closed. At the time, only about 10 of its 25 beds were filled.

"There was just a decreasing need for end-stage health care," says Ged Kenslea, the foundation's community relations director.

The house is now being refitted to accommodate patients who need short-term acute care, for example, those well enough to be discharged from the hospital but not well enough to take care of themselves at home. A similar shift is underway at two other hospices the foundation operates, though a small number of hospice beds will remain at each.

"I'm certain there will continue to be a need for hospice care. But there is no question the demand for our services has shifted," says Kenslea.

Through all of the bleak years of the AIDS plague, gay men and lesbians kept to the hope and dream of the day when we would see hospices close because they weren't needed

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