Check, Please

After a decade on disability, Joe Westmoreland is stuck between a buck and and a hard place.

August 1, 2004 By Joe Westmoreland

In June, I celebrated the 10th anniversary of a love-hate relationship: my dance with disability. What began as a ticket to liberation quickly morphed, when I fell gravely ill, into a desperate lifeline. Now, at 47, as I rebound under HAART and inherit a life I never expected, I view the monthly checks with gratitude and guilt. I need—and want—more.

It all began in mid-1994. With my T cells dropping below 300, I wasn't expected to live longer than a year. I assumed that for decent health care, I could never escape my soul-crushing word-processing job. Then GMHC sent me a letter explaining New York state eligibility for AIDS-related disability. My T-cell count qualified me for almost as much in disability as I was making full-time back then, approximately $45,000.

Freedom! I quit immediately—and, finally rid of corporate America, dyed my hair blue. I gave my office clothes to an AIDS charity and started wearing T-shirts and jeans. After this rebellious little honeymoon, I headed to the Social Security and NY State Disability offices to start the cash flow. I conquered the mountains of paperwork—and soon, monthly checks were deposited directly into my bank account. After taxes, they averaged almost $2,000 a month, barely enough to get by in Manhattan. Still, my income was guaranteed—and I felt like I was on shore leave.

Nine months later, the party ended. I started having fevers of 102 or higher every day. I became weaker and weaker until I wound up in the hospital with all kinds of tubes and plastic bags hooked up to me. I was surrounded by people who loved me, looking sad and helpless. But at least I didn't have to worry about paying for rent and utilities, medical treatment, cat food.

Thanks to my doctor and new HIV drugs, I pulled through. I still have fatigue, peripheral neuropathy, partial vision loss. Some days I can barely move. My lungs are scarred from pneumonia, and I have trouble breathing when it's hot and humid. Then there's the low-grade depression. Financially, physically and mentally, I feel retarded, behind by at least five years. I look around me and wonder when all my friends had time to advance in their jobs.

And my financial boon is becoming a burden. I get a slight cost-of-living increase in my disability payment, but it doesn't keep up with inflation. Insurance co-pays rise every year, too. Anything extra—a sick cat, dental work—sets me back into debt. I'm barely making it.

I fear the disability people will punish me because I’m not deathly ill all the time. If I want to stay in bed all day, they’ll cover me. But this in-between state—a long-term recovery from devastating illness—strands me between wanting to do more for myself and guarding my monthly checks. It’s true that I haven’t pissed away all those empty hours. I’ve published a memoir (*Tramps Like Us*) and am writing another. But for the most part, staying alive has turned into a full-time job. Sometimes it feels like I spend half my life going to doctors’ appointments and the other on the phone with my insurance company. So I look for ways of making money that don’t require a regular workweek.

Don’t get me wrong: I’m grateful for the payments. I love not having to work at a job I don’t like. That’s a definite T-cell booster. But when someone says I’m “lucky” to be on disability, it freaks me out. I’m not bilking the system: I worked long and hard at jobs I hated for this insurance.

What I really want is not to have AIDS anymore. When I get depressed and discouraged, I focus on what I can do, not what I can’t. My hair has gone from blue back to brown, but now with some gray climbing out. If only I could climb out.

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