



The Great Depression

POZ founder Sean Strub fell into one. Here's how he climbed out.

February 1, 2004 By Bob Lederer

In the mysterious, wacky world of HIV, it can take Nancy Drew to get to the bottom of a symptom. Case in point: Sean Strub's struggle last year with big-time depression. Strub, 45, started taking antidepressants in 1994, when the rat-a-tat-tat of AIDS deaths, his own failing health and (he believes) a genetic susceptibility plunged him into a funk. In 1999 his Zoloft failed and his shrink switched him to Wellbutrin, but for the most part, the drugs kept him smiling. Then, last year, his doc, Joe Sonnabend, MD, suggested changing HIV meds to avoid potential long-term toxicities.

Since 1996, when he'd nearly died, Strub had controlled his virus with Rescriptor (delavirdine), Zerit (d4T) and Crixivan (indinavir) with minor side effects, so this "if it ain't broken, don't fix it" guy initially balked at the switch. But last June, Sonnabend convinced him to start a protease-sparing regimen of Sustiva (efavirenz), Epivir (3TC) and Viread (tenofovir). Strub adored Sustiva's once-daily dosing. "It was so freeing not to take pockets full of pills with me everywhere," he says—and his virus remained contained. Strub was even more delighted when his hair, thinning for three years (probably due to Crixivan), began to grow back.

Strub knew about Sustiva's possible central nervous system disturbances—nightmares, insomnia, dizziness, disorientation, depression. They're common enough, but they generally clear up after a month or two. "The first three weeks were a little rough, with disturbing dreams and a spacey feeling," he recalls, "but I made it through and was proud of myself for handling the side effects."

By August, however, Strub "found it difficult to feel joy or get excited about anything," he says. "I assumed it was situational—I was stressed, doing too much." It also occurred to him that one of his new HIV meds might be lowering his blood levels of Wellbutrin. (Some HIV meds can interact with antidepressants; see "[A Tricky Combination](#)" and "[Beat the Blues](#)," POZ, March 2000.)

Spiraling into an intense depression, Strub says he "spent entire days in bed. Once, I didn't leave my house for four days. I'd cry at the drop of a hat, and then have a mania of activity for a few days. I'd never experienced that degree of emotional see-sawing. I knew something was seriously wrong and I reached out to friends—which is difficult, as anyone who's had depression knows." They pushed Strub to talk to a psychiatrist he'd seen in the past. (For more on battling depression, see "[Getting Down](#)".)

"When I finally called him, it was an act of desperation," Strub says. "I left him a message at 3

a.m., afraid that if I waited until morning I'd feel better and not call." The shrink urged him to ask Sonnabend about changing his antiretrovirals. First, Strub searched the Web. "I was astounded by the number of postings by people who withstood Sustiva's initial side effects, then later suffered moderate to severe depression, even psychotic episodes," he says. "It was a eureka! moment. I thought, 'I could have written that.'"

In October, Sonnabend recommended replacing Sustiva with twice-daily Viramune (nevirapine). Strub agreed but first opted for a treatment break. Within a week, his mood stabilized. "I felt like a cloud was lifting," he says. "I was no longer immobilized and could get back to work." A month later, when Strub's viral-load test came back undetectable and his CD4 count clocked in at 378 (robust for him), he decided to wait before restarting meds. Today, still off meds, Strub says he's in "terrific physical health."

Was Strub's slide into despair a fluke? It all depends on which expert—and study—you ask. In 2002, researchers at San Francisco General Hospital presented a two-year retrospective of some 200 HIVers on either the non-nuke Sustiva or the protease inhibitor Viracept (nelfinavir). Co-author Dan Karasic, MD, says, "There was a considerably higher rate of depression and anxiety [and other neuropsychiatric effects] among those on Sustiva [22.2 percent] vs. Viracept [2.2 percent], which continued over an extended time." Sustiva users with past psychiatric problems appeared especially prone. Another study, of 173 HIVers on Sustiva for three months or more, found that psychiatric symptoms "often persist" after the first month and "a significant percentage of patients" reported suicidal thoughts. Manhattan therapist Michael Shernoff, who treats many HIVers, says, "I've seen too many people get overwhelmed with unremitting despair until they get off Sustiva. No change of antidepressants helps."

Others argue that too much has been made of Sustiva's "mental problems" label. Cal Cohen, MD, research director at the Community Research Initiative of New England in Boston, cites three recent studies, totaling 3,000 people, that found that Sustiva-takers had only slightly more mood disorders than those on Viramune. A summary of clinical trial data by Bristol-Myers Squibb (BMS), Sustiva's maker, says depression strikes 15.8 percent of those on Sustiva vs. 13.1 percent of those on comparable medications. Cohen finds a lower number: "In my experience, maybe 5 percent on Sustiva have problems, either short or long term," he says. "Do people get worse later or are they just tired of tolerating it? It's unclear." Alan Schwartz, MD, a New York City shrink, also doubts the frequency of the Sustiva-depression link. "Most patients on Sustiva who I've seen get depressed are better within a month or two," he says. "I don't believe Sustiva is more likely to produce depression in someone with a history of depression."

And BMS's David Rosen says, "There are people who have trouble tolerating some medicines, so patients and physicians need to work together to create treatment regimens that keep the virus suppressed and improve quality of life. For a good number of people, Sustiva accomplishes this, but we recognize that it may not be right for everyone."

Federal treatment guidelines recommend Sustiva over Viramune due to its higher anti-HIV staying power (greater potency and durability) and Viramune's increased risk of skin rash and liver

toxicity. Of course, many on Sustiva do fine, with no long-term mood effects. For those wanting to switch, the good news is that most other HIV meds aren't as specifically linked to depression as Sustiva.

Strub says his bout with depression reinforced the importance of challenging any marketing spin minimizing HIV-med miseries to a getting-adjusted period. He urges everyone to read up carefully before starting any med, and be sure to tell your doctor if you have a history of depression. "Without a doubt," Strub says, "depression has been more invasive to my health and more frightening to me than AIDS has ever been, though I don't expect anyone who hasn't suffered moderate to severe depression to understand that."

Getting Down

5 mental-health dos (and don'ts) if you're at the end of your hope:

1. Reach out. If intense sadness and loss of interest or joy in normal activities last more than two weeks, friends or family can listen and lend advice. (Listeners: Encourage your loved one to see their doc or a therapist. Offer to accompany them.)
2. Don't assume. It may not be "all in your head." Depression affects 22 to 45 percent of HIVers, and its fatigue, lethargy and sleep disturbances can spring from such physical problems as low testosterone, nutritional deficiencies, some HIV-related illnesses—or your meds. Your doc should investigate all possibilities.
3. Find yourself...a mental-health pro with experience treating HIVers (ask your doc—or other HIVers—for a referral). Therapy and antidepressants can work wonders. Your shrink should be savvy about drug interactions and other HIV-specific issues.
4. Call 911 as a last resort. If you feel suicidal or if you're consistently not eating—and have nowhere else to turn—an ambulance will lead you to help.
5. Take heart. Thousands of HIVers have successfully kicked depression with a little help from their friends, psychotherapy, testosterone shots, antidepressants or a med change. As bad as it may seem now, you, too, can triumph.