Publisher’s Letter

March 1, 2000 By Brad Peebles

We have something in common, and it’s not just HIV.

In a recent survey of *POZ* subscribers, 71 percent of you told us that you’ve experienced depression. I hadn’t intended to mention the subject of our cover story in my letter—it’s about the difficulties of drug adherence—but after four false starts and seven rewrites, I see that depression is synonymous with writer’s block.

I expected to have no trouble at all writing about my struggle to adhere, but then again I also expected myself not to have that struggle in the first place. The simple fact is, I hate my pills, every single one of them. I hate looking at them. I hate putting them in my body. I hate the way they feel in my stomach.

Who hasn’t felt that? But each time I put this thought down on paper, I would freeze up. My words seemed full of self-pity and the column merely a list of ungrateful complaints. After a while I couldn’t get beyond the thoughts “You’re damn lucky to have the pills to take” and “You had unsafe sex with a total stranger—accept this as part of your ongoing, deserved punishment.”

I tell myself these things at pill time, two or three times a day, as part of an elaborate conversation in my head that is sometimes a cantankerous debate, other times an excruciatingly existential paralysis. A rational voice says, “Time to take your pills.” A chorus of other voices—some quiet, sad and defeated; some doubtful and paranoid; some confident, informed and determined to be the defiant exception—say: “Not now. Later.” The dissenting voices hold sway sometimes for an hour or two, and then I either overcome them and take the pills or give up and miss a dose.

I talk endlessly with my therapist, doctor and friends about my adherence problems. They all ask why it is so hard for me to take my meds. There are some pretty standard answers: The schedule and food restrictions are hard to manage; the pills make my stomach hurt. But part of the problem is that—aside from drug side effects—I don’t feel sick, and I don’t think sick. The viral threat seems abstract, existing only on paper. Treat it? Treat what exactly? I haven’t incorporated pill-taking into my survival mind-set. Pills are a several-times-daily reminder that I am sick, something I refuse to believe.

On the other hand, I know I have to take my pills. My self-confidence and my sense of well-being are inextricably linked to having an undetectable viral load. Without that I am greatly diminished. I learned this the hard way. It was this time last year that I went off meds—all of them. My

adherence had gotten so sloppy that I was doing more damage, by inviting resistance, than stopping treatment altogether would do. At first, my doctor and I discussed switching me to an adherence-friendlier regimen—a lower pill burden and an easier, more forgiving dosing schedule. But my difficulties weren't specific to the complicated regimen I was taking. I feel the same about every regimen. So we agreed that I should stop taking meds altogether rather than risk breeding resistance.

At first, I felt good, peaceful, with the decision. But after that, being off drugs didn't bring me joy or the exhilaration of freedom. The same HIV-related anxiety persisted. I couldn't help but think that it would be only a matter of time before my climbing viral load and falling CD4 cells made me go back on treatment. I held out for as long as I could. After three months, almost in tears, I told my doctor that given the lab work, I was ready to go back on treatment. But the hardest thing of all, I said, was realizing that there would never be a day when I was not on meds. I would be taking pills for the rest of my life.

"That is absolutely not true," he said. "I don't believe that for one second. There is promising research underway, there will be advances, a cure is possible. I believe that and so should you."

I sat there as the smartest man I know, the man I trust my life with, expressed really meaningful hope. Hope not just for survival and living with a chronic illness, but for a once-and-for-all cure. I wanted to believe him.

At *POZ*, one of our jobs is to give people this kind of hope. When I do that, in my role as publisher, I'm not lying—I do believe it. But sometimes I don't believe it for myself, as a person with HIV. So even if this letter doesn't supply hope, let alone a successful strategy for drug adherence, it at least tells the truth. And there may be hope in that.

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