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After only two weeks off therapy, my viral load skyrocketed from undetectable to over a million.

September 1, 1998 By Sean Strub

I conducted an unfortunate experiment a little while ago. It's embarrassing to relate, but I think it may be important for others on antiretroviral therapy to hear.

A few weeks ago, just before the World AIDS Conference in Geneva, I went away for four days and forgot to take my triple-combination-therapy drugs with me. I had been fairly adherent since beginning therapy in January 1996, but in this instance I just decided not to worry about it for those four days. There has been a lot of talk among researchers and activists about people who have gone off therapy, some with apparent success. I was curious, and since I couldn't take my drugs for a few days anyway, it seemed like a good time to experiment.

Those four days were liberating in a way I had forgotten was possible: No constant drug-induced anxiety, no stomach aches, no shooting neuropathy pain in my feet. I ate whenever and whatever I wanted and was even able to sleep through the night without interruption.

There was also the pleasant psychological effect of being severed from a pharmaceutical tether. I felt like I had cast off 17 years of the epidemic and years of accumulated treatment frustration. Maybe I was, finally, past AIDS.

So when I got back home to New York City, I decided to stay off my treatment for 10 more days—a total of two weeks—and see how it went. I liked the idea of flushing out my system and finding out how well my recovered body could handle no treatment.

At first, I wasn't at all nervous about going off treatment. The few people I told of my decision—including my doctor—were alarmed and strongly disagreed. They didn't understand the newfound freedom I felt. Going off treatment felt so right, I couldn't imagine it could be wrong. Besides, I promised, it was only for two weeks.

But, for me, it was a mistake. A big one. Within a few days, I developed profound fatigue—similar to what I had felt at the depth of my sickest point, right before I began therapy. My lymph glands swelled dramatically, I had headaches and an overall feeling of malaise. I couldn't work or write.

Even so, I thought maybe I just had a flu. I vowed to see my experiment through and stay off

therapy for the full two weeks. At the two-week point, I had blood drawn to check my counts.

My viral load had been essentially undetectable for two years. Not anymore. After only two weeks off therapy, my viral load skyrocketed to over a million and my CD4 cells plummeted almost by half, to 154.

I raced back to my therapy, feeling almost as if I should take “extra” to try and stomp out the newly rampant virus in my blood even faster. This was a case of fear=adherence.

I don’t know how much damage this break in treatment has caused, or whether I’ve facilitated the development of resistant virus or impaired efforts to repair my immune system. But I do know my few euphoric days of freedom were not worth it.

The instinct to abandon the tyranny of treatment, especially when one is simultaneously in good health and suffering from side effects, is understandable. Most people with AIDS I know find it easier to be adherent with their treatment when they are feeling sick.

At the Geneva conference there was talk about “subtraction” therapy, new theories about supposed HIV eradication strategies and a discussion about a few special cases of people who went off therapy without apparent ill effects. I wish this research the best of luck, because the desire to abandon treatment is only likely to grow with the passage of time.

Until we know who can go off or reduce treatment, and why, people are going to continue to experiment and find their own paths—as we’ve had to since the first days of the epidemic—with some of us paying a heavy price along the way.

In the meantime, I’m retiring my guinea pig hat for a little while.

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