Week On, Week Off

Structured treatment interruptions gave Shawn Decker a better quality of life—and a trip to the emergency room.

March 1, 2009 By Shawn Decker

In the classic ’80s flick The Karate Kid, Daniel-san doesn’t quite understand how doing Mr. Miyagi’s chores will help him accomplish his ultimate goal: beating the hell out of those karate-jerk bullies from the Cobra Kai dojo. “Wax on, wax off?” he thought, dismissing the old man’s wisdom, figuring his time would be better spent otherwise.

In the summer of 2000, I experienced a similar doubt-filled situation while attending my first memorial service for a pal lost to the disease—AIDS activist Stephen Gendin. Another well-known AIDS activist, Larry Kramer, was on hand to deliver the eulogy. He railed against pharmaceutical companies, bemoaned the fact that he’d lost his derriere to the side effects of his HIV drugs and advised all the “positoids” in attendance to stick it to the drug companies by taking our meds half the time.

“Half the profits!” Larry barked, reinforcing why we should stick it to the man. As he bristled, the thought of playing with my treatment seemed as reckless as washing windows to prepare for a karate fight. After one year on meds, my health was turning around. I’d made peace with the fact that side effects were just part of the bargain.

However, in the months after the memorial service, my attitude started to shift. After a year into my second set of mind-numbing drugs, I desperately wanted to reclaim my quick wit and ability to stay focused in a conversation. Perhaps empowered by an undetectable viral load and rising CD4 count, I started to allow my unclear mind to consider a structured treatment interruption (STI), a.k.a. “drug holiday.” To my delight, my doctor didn’t shoot the idea down. In 2002, we decided that I’d do one week on my HIV drugs, followed by one week off. Part of the deal, however, was that I had to wash Dr. Greg’s car on the weekends-—wax on, wax off.

After four weeks, I went in for lab work: My viral load was still in check, and my CD4 count continued to rise. I was enjoying the benefits of fewer side effects—so much so that I began to fantasize about having even more freedom from my HIV regimen. How great would I feel if I took two or three weeks off from my meds?

In 2005, I decided to find out. My excuse was to clear my head, so I could finish my first book. Dr.

Greg was against the idea, but I was adamant. I took four weeks off, but my CD4 count dropped from 460 to 334. “Whatever, CD4 counts fluctuate,” I thought. My still undetectable viral load gave me a false sense of security. One month later though, on the morning of my follow-up labs, I was back at the hospital. Only this time, I wasn’t casually joking with Dr. Greg in the infectious disease clinic. I was in the emergency room.

HIV—my “pet virus”—was mauling me. Idiopathic thrombocytopenic purpura (a blood clotting and bleeding disorder) put me in the hospital all weekend. It was a direct result of stopping my meds. Admitting that my judgment had been so wrong was a tough pill to swallow.

The good news was that I rebounded quickly after getting back on HIV meds. Within a few months, I’d broken a personal record for CD4s: more than 600! Even so, it took a year to feel comfortable enough to give the “week on, week off” treatment strategy another go. It’s a treatment strategy that I’ve continued to use since 2006.

It’s funny to think back to that memorial service and Larry Kramer’s impassioned words. Back then, I was baffled at the suggestion to break the status quo. Now, I’m just as baffled that no one else is doing it. Any time I read about structured treatment interruptions they are universally dismissed as being dangerous, even potentially fatal and yet, the evidence is still coming in.

After my ill-advised two-month drug holiday, I can see the reasoning. This virus is deadly serious. But, in my case, there was a huge difference between one week off the drugs and eight weeks. I’m not suggesting that this would work for everyone, but I’d feel guilty if I didn’t reveal the long-term success that I’ve experienced.

Ultimately, my decision to continue this is based on one thing: quality of life. That is one thing I’m determined not to lose.

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