Publisher’s Letter

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Thoughts of living forever once came naturally to me. This fantasy of immortality was about being young and fearless and having a boundless expanse of time before me as I embarked on adulthood. “Forever”—the realistic version, at least—meant a full, long life. When I tested positive, forever disappeared.

Fear quickly replaced my optimism, and I began trying to adjust emotionally to a dramatically shortened future. For example, I wanted to go to graduate school at night but feared I’d be ruining the time I had left with stress and extra work. Why even invest in a long-term future? But no matter how real the possibility of sickness and death felt to me, I somehow knew I had to live my life—in actions if not fully in feelings—as if it would be a long one. (By the way, I graduated last year.)

Thanks to that knowledge—and amazing HIV-drug advances—I’m now counting my future in decades rather than years, and slowly regaining that faith in “forever.” But paradoxically, reconciling the prospect of continuous treatment with the longer life it has provided has been harder. When I thought I had five years to live, I was much more willing to take drugs that worked for a limited period and to endure their side effects. But when I began to think about being here another 30 or 40 years, the all-pills-all-the-time standard of care—which, after all, was born out of crisis and is inherently short term in design—no longer made sense. How was I supposed to take these drugs forever?

So when my viral load became detectable in 1997 after switching regimens due to side effects, I decided to stop meds altogether. It was difficult to persuade my doctor to go along, and I found little support from fellow HIVers. In my mind, the treatment break was as much a treatment action as any pill regimen, but few others saw it that way. No research on STIs had yet been done, and stopping HAART was viewed as a dangerous invitation to disease progression. Even though I made the decision carefully, I felt foolish, dumb and—most frightening of all—alone.

As predicted, my viral load went up and my CD4s dropped. After four months off treatment—amidst a chorus of “I told you so”s—I started back on a recycled regimen. Fortunately this combination worked, and I was right back where I had started: doing OK on treatment, confident in my survival and questioning everything.

Now I’m on my third treatment interruption. (How am I doing? See “Club No-Med” for my stats.) I’m fairly convinced I’m doing the right thing—for me. But I still have doubts: Will I die sooner than if I had spent the past six years on HAART with an undetectable viral load? No one knows. As this month’s cover story, “Gimme a Break,” by Mike Barr, shows, research has a lot of catching up to do.

What was seen as an irresponsible anomaly in 1997 is now an undeniable trend: For better or worse, more and more HIVers are trying STIs. The individual reasons are many and diverse, the data few and inconclusive. But the writing is on the wall: Being in care does not always mean being on treatment; there may be times when the best regimen is none at all. Is today that time for you? Only you and your doctor can make that decision. What I can tell you from my own experimentation is this: When I’m on treatment, I think about being off; when off, on. So while my future is likely to include more pills and more breaks, I’m still waiting for what I imagine would really give me that forever feeling: a break from HIV.

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