Killing Me Softly

When HIV progresses from stressful to lethal

April 1, 1998 By Stephen Gendin

For 12 years I've had HIV, more or less without symptoms. So I've long thought of it as an emotional burden, never a physical threat. Now, suddenly, at a gut level, I understand that it can kill me.

Last October, I started a seven-drug antiviral combination, and things quickly got out of hand. I was camping in rural Tennessee with my boyfriend. There were few amenities; the nearest outhouse was a 10-minute walk from our tent site. Despite mouthfuls of Imodium, each day my diarrhea got more explosive and unpredictable, and I often didn't have 10 minutes' warning. So I started squatting in the woods. At night, naked and barefoot, I would crawl out of the tent onto the damp earth, tripping over branches until I found a spot. Back in my tent again, shivering, I felt much like an animal.

With HIV, symptoms usually come in clusters, and my case was no exception. The diarrhea dehydrated me. The drugs dried out my mouth, and I couldn't swallow the whole-grain breads or the dry rice and beans that were our standard rations. And my sense of taste was screwed up, so while I should have been eating a lot more than usual to counter the diarrhea, my food intake instead dramatically decreased. The results were predictable: I began dropping pounds fast.

Although I knew I was losing weight just by looking at my face in the mirror -- my cheekbones sticking out, my temples hollowed out -- nothing prepared me for the strange glances and strained comments I got upon returning home. Friends and coworkers couldn't help asking me, "Have you lost some weight?" But when I'd answer vaguely and steer the conversation in another direction, we were all relieved.

People must have sensed how unwilling I was to discuss the subject because no one ever truly challenged me about my health. But as the questions and stares accumulated, I began to get angry. I didn't understand why people were harping on me so much. I felt harassed. I never interpreted the comments as concern; the attention just left me wanting to lash out.

I also began having frequent dizzy spells, the kind that happen when you stand up too quickly. I considered calling my doctor, but since I already had an appointment in a week, I decided to wait. Of course, the diarrhea only got worse. One morning, while traveling with a business associate, I woke up to discover I had shit my underwear and bed. I was humiliated. Every night after that I

went to sleep filled with anxiety, never knowing if my body was going to turn against me.

I could tell my boyfriend was worried, even though he wasn't showing it. A vegetarian, he is usually unwilling to cook meat for me, but after our return he made me steak. Twice. We discussed my weight loss, in a carefully casual tone, and agreed it wasn't a good thing. That was essentially how I had come to think about it: Not good, but certainly no emergency. I just wasn't registering all the comments and stares, and most were easy to dismiss because they were delivered so timidly. That is, until I complained about this state of affairs to my HIV support group and heard one member say, "You know, your face really does have that AIDS look." There was a terrible silence. Then we moved on.

Finally I visited my therapist and got The Lecture. He was uncharacteristically sharp with me, saying I was seriously ill and in need of an emergency doctor's appointment. I tried to shrug him off, but he wouldn't back down, insisting I call my doctor as soon as the session was over. I left with a swirling mass of confusing emotions. Angry at him, I also began to feel real fear for the first time.

The next morning I saw my doctor. I was told I was severely dehydrated and had to be immediately infused with two liters of saline. I had dropped 15 pounds in 20 days. My blood pressure was dangerously low. My blood work showed signs of kidney strain. My doctor scolded me for not calling earlier. Only after all this did it sink in how close my body had been to complete collapse.

How could I have been in such denial? I'm usually such a take-charge kind of guy, but I had let this situation spiral wildly out of control, causing myself a lot of avoidable damage. All I can say is, I just wasn't ready to accept that I have finally hit that stage where HIV is affecting me day-to-day, limiting my activities, putting my very life in immediate jeopardy. But I have.

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