How Am I?

Don’t ask

December 1, 1998 By Stephen Gendin

I get asked about my health all the time, but I hate talking about it. Every conversation reminds me how precarious my situation is. Discussing “how I am” usually seems like either idle chatter, the obligatory effort to keep everyone current or a plea on my part for sympathy. But I don’t want quick answers or momentary support—I want CD4 cells—and talk gives me none.

This habit of keeping quiet annoys. My father, for one, wishes I would give more frequent and detailed updates. He has had to resort to discussions with my lover, Hush, to get the facts about CD4s, viral loads, symptoms and meds. It may be cruel to keep him in the dark, but I have to provide so much scientific background that I feel like I’m giving a lecture rather than getting support. Breaking down my health crisis into bite-size, easy-to-digest chunks is hard work, and I’d rather save that energy for myself. Call me selfish.

My lover would also appreciate more information. But what Hush demands is less the hard data than the soft: He wants to know my *feelings* about my health. Since HIV has so powerfully shaped my life, he feels disconnected from me when I keep quiet. But feelings are something I’m even more reluctant to discuss. The truth is, no meds are working for me, and I’m sure to come down with something serious soon. It’s a depressing fact, so in general I avoid even thinking about what awaits me. And since I’ve always been such a take-control kind of guy, my unwillingness to “share” is more an attempt to avoid feeling really low than a desire to withhold information.

If I feel comfortable talking to anyone, it’s my treatment-activist friends, most of whom are positive. Having ridden the AIDS rollercoaster for so long, we’re nonchalant even when being whipped upside down. We’ve developed a jaded, heard-it-all-before approach that keeps the conversation light despite the fact that the subject is deadly serious. Our shared jargon is shorthand for much that we prefer to leave unspoken, and while feelings are mentioned, we know not to dwell on them because that path leads to despair. We’re more likely to debate the science of new therapies than to confess the panic bubbling up in the pit of our stomach.

In my HIV support group, there’s a thread of conversation that ponders the objective of our weekly meetings and wonders what good will come of all the soul-searching. The four of us know the “correct” answer—by becoming conscious of our fears, we free ourselves from them—but sometimes that response seems like a bunch of bull. Often the conversation does nothing more

than upset us, and we walk out the door feeling lower than when we came in. Still, we keep coming back. But there are times when I think I'd feel much better just staying home watching *Seinfeld* reruns than sitting in a therapist's office for an hour and a half trading treatment worries.

This hesitancy to talk about my health is not, contrary to popular belief, a form of denial. In fact, I consider it the opposite: an acknowledgment, if not acceptance, of my condition and a wise decision not to despair over a reality I can't change. My silence is *chosen*. There's no single best way to respond to an AIDS diagnosis, and my method seems to work for me. I've managed to keep functioning despite my dreadfully low CD4 cells and high viral load. By not dwelling on these dismal facts, I maintain the momentum of my life. I worry that even a moment of introspection could lead to inertia, to a quagmire of malaise.

Perhaps I exaggerate. I am, after all, a professional PWA, someone who makes his money and spends his days talking to people about difficult treatment decisions. Usually I manage to treat my work like any other job, but occasionally something slips past my barriers and—whammo!—I'm down for the count.

The first time this happened—in early 1993 after my diagnosis changed to full-blown AIDS—I was a wreck for months. It took many weekly massages and acupuncture appointments, plus a whole lot of Xanax, before my back unknotted and my colon stopped spasming. I'm just no good at putting myself back together.

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