On The Runs

Meds made a mess of his intestines and self-esteem. Now, with this Diarrhea Diary, former slave to the porcelain Stephen Gendin shares his dirty laundry.

April 1, 2000 By Stephen Gendin

April 1998. I've finally had enough. Last night, my friend David and I were walking home from Lost in Space, and I was lamenting that the actor playing Will in the movie wasn't nearly as cute as the '60s-TV-show one, on whom I've had a crush for two decades. In the midst of praising the old Will's many virtues—innocence, freckles, patience—I felt the telltale rumblings in my stomach. It was the Diarrhea Express picking up speed as it choo-choo'd through my intestines. I knew there was no stopping this juggernaut until it unloaded its cargo. The only question was where.

It was past midnight on a dark residential street. There were no open restaurants to suavely tiptoe through, pretending to be looking for my table while I determined where the bathroom was. No bar. No library. No health club. I felt the urge to run, but giving into the terror always causes me to lose control of my sphincter immediately. Should I inform David of the emerging crisis or remain nonchalant? Why did I ignore the early warning twinges back at the theater? Suddenly it was too late. I knew I had less than 30 seconds, so I started hunting frantically for an alley or a dark doorway. All I found was a little parking lot between two buildings.

Scuttling into the deepest shadows in the back, I just managed to pull down my pants before the explosion. Then I had to creep around the lot, searching for scraps of paper to wipe myself. Staring at David's politely turned back, I felt the same sense of shame I sometimes see flicker across my dog's face on those rare occasions when I ignore his whining for too long and he pees in the apartment.

Well, I refuse to wear adult diapers. So what's left? Today I'm stopping all my antiretrovirals.

October 1998. I feel like I've died and gone to heaven. My biggest daily burden—diarrhea—has been lifted. It didn't disappear overnight, but every drug-free day is a little better than the previous one. I envision my intestines slowly healing as they recover from a decade of antiretroviral abuse. I walk around town all spiffy and proud, knowing that the odds of returning home with dirty underwear are slim—a secret joy. It also wasn't until this anxiety began to lift that I was able to assess just how much energy I've wasted in recent years worrying about my watery nightmare.

May 1999. I’m about to start antiretrovirals again. As much as I’ve loved the break, it isn’t “prudent” to remain off meds given my off-the-scale viral load and vanishing CD4 cells. I probably would have restarted even earlier if not for my terror of side effects. Preparing to take these pills feels like willingly subjecting myself to a hot poker up the ass or drinking molten lava. Usually I’m a pretty optimistic fellow, but I see a long, dark road ahead. Taking Norvir and Videx together will likely be intestinal suicide. In preparing for my first day back on the regimen—tomorrow—I’ve been loading up on Imodium, taking as many as 10 pills a day. My strategy is to stop up my system with roadblocks to prevent the juggernaut from breaking through. Like a prisoner on death row, I count down the days I have left. Will it be a week or a month before my system is a wreck again? The uncertainty is so unsettling.

Besides the side effects themselves, the thing I hate most about taking my pills is the drug-company propaganda that the side effects aren’t so awful and fade away over time. Having spent years on AZT monotherapy with no complaints, I know that is sometimes true. But since going on triple-combination therapy in 1993, the side effects seem to grow with each passing day. So, it royally pisses me off when I encounter what feels like a massive conspiracy to minimize the consequences of swallowing large quantities of often-toxic medicine. I would rather be dealt with honestly.

November 1999. What a surprise! Seven months back on therapy, and the diarrhea hasn’t been too bad. It’s there, but my daily downings of Imodium control it, and I haven’t ruined any underwear yet. The time off from the meds must have healed my intestines, making them strong enough to resist the Videx/Norvir punch. Now I wonder: Since my fears turned out to be unfounded, should I have gone back on therapy sooner?

Maybe. But I’ve learned that there isn’t much point in second-guessing my past treatment decisions. I’m still here, and that’s what counts.

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