POZ Side FX

September 1, 2000 By Spencer Cox

In Roman Polanski's 1965 film, *Repulsion*, the lovely, young Catherine Deneuve plays a manicurist who, alone in her Paris apartment for the weekend, goes bonkers. As the hauntingly black-and-white story is told from her increasingly deranged perspective, it takes the viewer a while to figure out what's real and what's imagined. Is there actually a brutal rapist knocking on her bedroom door in the middle of the night? Whose hands are grabbing at her from the hallway walls? And why does the living room keep changing size? When I first saw the movie, I had nightmares for weeks.

By contrast, the nightmares I had while taking Sustiva (efavirenz) were only too real, lasted for months and made Repulsion look like a Disney musical. You see, Sustiva has side effects, or fx, as they say in beautiful and damned Hollywood. Not infrequently, these fx are—as I found out, Polanski-style—bad ones. I became so depressed that I couldn't make it through an episode of *The Rosie O'Donnell Show* without bursting into tears. At night, I'd dream of being visited by old friends who have been dead for years. And on more than one occasion, I'd get so disoriented while grocery shopping that I'd have to sit down in the middle of the aisle until I figured out where I was. By the time I went off the drug, I was feeling like the last reel of an *E! True Hollywood Story*.

Desperate to know what was happening, I finally read the densely printed text on the endlessly folded little piece of tissue paper that comes with the pill bottles (known as the "prescribing information," "package insert" or "PI"). There, in type so small I needed a magnifying glass to read it, I found the following: "Serious psychiatric adverse experiences have been reported in patients taking Sustiva…," including "severe depression, suicidal ideation/attempts, aggressive behavior, paranoid reactions and manic reactions." To put it plainly, the drug can make you as nutty as Catherine Deneuve in *Repulsion*.

Other drugs' special effects can be equally surreal, as I've learned in my nearly eight years of being on AIDS meds. Having experienced just about every undesirable attribute these drugs can offer, I've come to think of myself as the Pearl Mesta of side effects—the hostess with the mostest, if you will. For this reason, POZ has asked me to introduce you to "Beyond the Valley of the Dolls," this up-close-and-personal look at abdominal pain, aggressive behavior, anemia, bone loss, buffalo humps, diabetes, diarrhea, fatigue, gas, insomnia, kidney stones, muscle loss, nausea, neuropathy, pancreatitis, paranoid reactions, severe depression, taste perversion, vomiting, and so much, much more.

Although all 14 anti-HIV drugs may cause side effects, it doesn't mean that you'll necessarily suffer them—unless, of course, you happen to be me. For instance, while I was praying for a swift death while taking ritonavir (Norvir)—I'll spare you the colorful stories—a friend breezed through the drug without a single problem. For many reasons, it can be hard to determine how likely it is that you'll get to experience a particular side effect. According to the PI, only about 3 percent of people taking Sustiva in pre-approval studies had to stop using the drug because of side effects. But most of the other volunteers must've been pretty butch; several docs have told me that as many as one third to one half of their patients can't tolerate Sustiva. Oddly, it always seems that subjects in clinical trials withstand drugs better than real people like you and me.

For almost 10 years, the Food and Drug Administration has approved life-saving drugs based on short-term studies involving few people. Sped-up approval has also meant that we come face to face with the full range of possible side effects only after the meds hit the market. It follows, then, that when choosing any AIDS therapy, HIVers should consider not only what those glossy ads' small print says about side effects, but also the potential risks that aren't known. A rule of thumb: The newer the pill, the more likely that unforeseen extra effects will turn up—quite possibly when you're the patient popping it.

A notorious example, of course, is lipodystrophy, the series of bizarre changes in the body's way of processing fat. It wasn't until doctors began handing out HAART like candy that people started experiencing this scary syndrome. Sometimes, HIVers lose weight in the arms, legs and face, but gain fat inside the abdomen or in deposits just above the shoulder, often resulting in disfigurations colloquially called buffalo hump, puppet face, protease paunch, tits on sticks (see "The New AIDS Look," POZ, June 2000). These metabolic mishaps may also involve elevated levels of cholesterol and triglycerides as well as increased risk of heart disease. We don't really understand such abnormalities, but researchers are currently studying them, trying to figure out why they happen and what can be done to treat or prevent them.

HIV drugs' side effects can be quite serious, and sometimes your doctor may not know to look for them. Don't stand on ceremony: Whether you're new to a med or an old pro, report any unusual sensation—abdominal pain, fatigue, headache, anything—because it may be a sign of a worrisome side effect. After all, while la vie positive is not a cabaret, it also should not be a trial by fire, so don't be a martyr to misery. By working with your doc—to change doses, add remedies, switch regimens or take a break—you can often find ways to at least minimize the drug-related nasties.

Mercifully, anti-HIV therapy is constantly evolving, most recently in ways aimed at dealing with side effects. Some of us may have survived long enough to remember the earliest days of AIDS treatment with AZT. Back in those dark ages, doctors prescribed doses nearly three times today's, with horrendous side effects: Foremost among them, perhaps, was severe anemia and "AZT butt," a bizarre wasting that reduced rounded rumps to shapeless sacks. Later studies showed that a much lower AZT dose was equally effective at fighting HIV, and had far fewer side effects. Norvir, similarly, is now used at lower levels in combination with another protease inhibitor than when first prescribed, with diminished ill effects. We've also found that starting with a low dose of nevirapine (Viramune), then gradually increasing it over time, can reduce serious drug-induced rashes.

Drinking a lot of water dramatically lowers the chances of Crixivan-caused kidney stones, while eating a high-fat meal may minimize nausea and vomiting with Norvir.

Preparing for side effects may give you a greater sense of control. You can have the antidiarrhea medicine ready or learn the symptoms of anemia before it strikes. Unexpected side effects can be demoralizing, but knowing what they are and what can be done can help limit their anxiety-producing potential. We're learning more every day and, I hope, working our way toward kinder, gentler regimens. After all, people don't like to buy drugs that make them feel lousy, which increasingly is inspiring drug companies to frantically search for more user-friendly meds. Bristol-Myers Squibb, for instance, is currently working on a new formulation of ddI (Videx) that the company hopes will cause less diarrhea.

To put it mildly, drug side effects stink. So why do we endure them? Because they are better than the alternatives—an ugly AIDS death or crippling opportunistic infection. There are now lots of data showing that anti-HIV therapy can dramatically lower the risk of life-threatening infections and death in people with advanced disease, while other, less rigorous studies suggest that HAART has benefits for healthier HIVers, too. But there's no denying that finding treatments that are less unpleasant than the disease can be tricky, and then some.

Hopefully, this issue of *POZ* will help you—especially those now considering starting the journey on med road—make choices with a fuller understanding of side effects and how to cope with them. With that said, enjoy the trip. And remember: We who are about to run to the bathroom—again—salute you!

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