Resistance Is Futile

Shari Margolese's teenage son still needs her nagging ways to get him to swallow his HIV meds every day.

January 1, 2009 By Shari Margolese

Minimal response and resistance. Each day, when I try to wake up my 16-year-old HIV-positive son to get ready for school, I expect minimal response and a little resistance. When I ask him to clean his room or take out the garbage, I expect minimal response and a little resistance. When I ask him to take his meds, I expect a modicum of reluctance (I mean, who likes taking pills every day?). But his total resistance took me by surprise. Not his resistance to downing the lifesaving meds, but rather his body's resistance to the treatment. I thought his compliance was excellent so I didn't expect his HIV to become totally impervious to his medication.

When I first heard that his drugs were no longer suppressing his virus, I wasn't truly shocked. A few months earlier, my son's viral load "blipped"—a cutesy term to describe a temporarily detectable viral load. But over time, the "blip" turned into a "blimp" and it became time for genotype testing to check for drug resistance. My boy's virus isn't resistant only to his current drugs; it is either resistant or has minimal response to all nucleosides and non-nucleosides currently available.

Over the years, each time we visited the doctor the question to my son remained the same: "Since I last saw you, have you missed any doses of your medication?" The answer was usually: "No." But as we watched his viral load climb, there was reason to believe that he was not taking his pills daily. At our last visit my son admitted that he hadn't been taking his meds regularly, and I was forced to admit that I hadn't even noticed. I was overwhelmed with guilt. How did this happen?

It's hard to take medicine every day. I've been doing it myself since 1996. My son has taken meds since he was 18 months old. As a youngster he was easily persuaded to take them with the promise of a chocolate milk chaser. And if that didn't work, he was small enough to hold down! Today, at 16, he's nearly 6 feet tall and weighs 175 pounds—no longer easy to persuade and now impossible to hold down.

My philosophy has always been that he needs to learn to be independent about taking his meds. Since he was a tot, I engaged him in the process. He extracted the liquid formulations from the bottle with a needle-less syringe. He later filled out the drug planner— recording not only his own pills, but also mine. My constant reminders of, "Did you take your meds, son?" were met by the

reply, “Yeah mom, did you?” As he grew older, I stopped nagging, feeling confident that he had become responsible about taking his meds. For a while, my plan seemed to have worked. He was a healthy, buff young man with a solid chance for a bright future.

So how did we end up in this drug resistant nightmare?

I wonder whether recent family turmoil spurred him to skip doses. His dad and I split this year, and we had to move to a new home. On top of it all, his dog died. Was it just too much for him to handle? Or perhaps it was simpler than all that. Maybe he didn’t feel sick and couldn’t see the point of downing the drugs. “Why did you lie about taking your meds, sweetie?” I asked, hoping my gentle tone would extract the truth. In typical teen manner he replied, “I don’t know.”

Perhaps we’ll never know for sure why he didn’t stick to the program. Possibly a simple case of teen invincibility. Maybe even pill fatigue—grown-ups get it all the time.

For now, I am back to nagging and daily pill counting to ensure that he gets back on track with his new regimen and doesn’t develop further resistance. While the constant cry of, “Did you take your meds?” continues to be met with a touch of teenage reluctance, I am determined that from now on, we will overcome that reluctance to avoid more HIV resistance.

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