

Adhere Say

Phill Wilson bucks the trend and says “later” to his protease cocktail

March 1, 1998 By Interview by Manjula Martin

Phill Wilson is just saying no to drugs, but not the ones Nancy Reagan had in mind. Last summer, the former director of public policy for AIDS Project Los Angeles stopped his triple-combination therapy, despite an undetectable viral load. Wilson (profiled in POZ June/July 1994) has always regarded his work as an integral part of dealing with his illness. Now stationed at the University of Southern California, where he's building an archive on AIDS social policy throughout the epidemic, Wilson tells POZ what led to his dramatic change in treatment philosophy and regimen.

How have you been feeling?

I've been very good, relatively speaking. One and a half years ago I was in an intensive care unit for a week -- I had congestive heart failure and developed an infection in the lining of my heart, and then I had pneumonia. Today I'm in a very different place. I've been able to normalize my illness so that I can live with it.

You recently stopped all your HIV meds. What were you taking before this decision?

In the past few years, I've gone from monotherapy [with AZT] to two-drug therapy [with d4T and 3TC] to triple combo [with saquinavir (Invirase), 3TC and AZT]. The whole time I was taking Bactrim as a PCP prophylaxis and acyclovir [Zovirax]. The double combo reduced my viral load to about 5,000, but since I unfortunately didn't get a baseline count when I started, I don't know how high it was before. On the triple combo my viral load went to undetectable. In June 1997 I stopped everything. My last viral load count, in September, was 3,000.

You had an undetectable viral load -- the combination seemed to be doing its job. Why did you stop?

I had always felt that it would be difficult to adhere to a regimen that I had to take more than twice a day, but I originally agreed to go on the triple combo because I was convinced the data warranted trying it, and I was caught up in the flow -- everybody was talking about it and doing it.

But the feeling of being trapped by this difficult regimen, as well as the constant nausea and diarrhea, created severe depression. I found myself accidentally missing or forgetting dosages. I would either completely forget, or I would get up and make breakfast so I could take my meds with my meal and then not remember if I had already taken them or not. Or I'd go out of town and forget them at home. I said, "What's going on? I'm smart enough to maintain this, I have a good enough

support system." Theoretically, I should be an adherence poster boy. But I'm not.

Why not?

In order to succeed with these drugs, I had to be emotionally ready to do this for the rest of my life, and I hadn't done that work yet. My doctor and I agreed that rather than risk missing doses, I would just stop. It wasn't because I stopped believing in combo therapy or because the drugs weren't working -- it was actually the opposite. I believe that for some people, including me, these or future combos will work. I stopped because I wanted to make sure I maximize the potential for taking this regimen. I intend to eventually go back on therapy.

What are you doing to get yourself emotionally ready for that?

In addition to seeing a counselor, doing yoga and having massage therapy, I've been spending a lot of time talking with people. One of the ways I've always dealt with my own illness is to turn my personal issue into a policy issue, because I'm a policy wonk of sorts. So I've been doing a lot of work on adherence.

What have you found?

I have this belief that once you have knowledge, you can break through barriers of all sorts. And certainly a lot of folks don't understand the importance of adherence. But I've realized there's a larger population that does understand; however, knowledge alone is not sufficient to get them to adhere.

What else do you think is needed?

Doing your emotional homework. It's essential to have some sort of understanding about what you want out of life -- and your quality of life -- before you commit to this.

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