A Load on His Mind

Tom Morgan’s antiretroviral crisis of faith

October 1, 1997 By Manjula Martin

Tom Morgan was always first in line to try a new drug. But after seven years of striving to be at the forefront of AIDS treatment, Morgan (profiled in *POZ, April/May 1995*) inhabits a body that has viral strains resistant to most meds. A board member of Gay Men’s Health Crisis, former *New York Times* reporter and former president of the National Association of Black Journalists, Morgan is experiencing a crisis of faith. Quiet yet eloquently expressive, his voice holds a certain sadness--and a subtle anger--when he speaks of his treatment history and options. From the Brooklyn brownstone that he shares with his partner, Tom Ciano, Morgan tells *POZ* about his frustrating course of antiretroviral therapy.

POZ hasn’t talked with you since 1995 -- how have you been?

I’m in crisis, actually. I’m not having success with protease inhibitors. I’ve taken every single AIDS drug there is, and my body’s built up resistance. The mutated virus in my system is used to every drug, so when I add a protease into the mix, it works for a little while and then stops.

I’m currently on high-dose (1,000 mg) Crixivan with d4T and 3TC. I had been taking nelfinavir (Viracept), but in late May I stopped because it didn’t do anything. Since 1990, my viral load has ranged from 40 to as high as 400,000 on my last test. My most recent CD4 count was 62.

Have you tried any complementary therapies?

I’m weight training, I do yoga and I garden in our backyard. I also take vitamins and minerals (including E, C, selenium and zinc) and I try to eat balanced meals.

I took blue-green algae for a while. It didn’t do any harm, but I couldn’t see any difference, so I lost faith in that.

I’ve had more than a year of battling with diarrhea, mainly because of the protease drugs, so I take Lomotil (diphenoxylate) with every cocktail. I think I have it under control now.

Are there any real treatment options for people who’ve built up resistance?

Long-term survivors like me are largely up a creek, because we can’t get access to new drugs in the pipeline. Pharmaceutical companies have something called “salvage trials” for people who’ve failed a particular drug. But unless you’re newly infected or haven’t had much treatment, you

won’t qualify. I’ve also tried to get “compassionate use” access to new drugs [a program by which a doctor can apply for special permission to prescribe an experimental treatment], but I’ve gotten nowhere.

Do you think people are aware of the difficulties in getting drug access for long-term survivors?

A lot of people think the war has been won, and we’re having to fight at a different level. Now the real challenge for AIDS activists is to get expanded-access programs for people who are failing drugs. Even if I can’t fit the narrow confines of a clinical trial, I want access to that drug! That’s my frustration, and that’s also my anger.

What would you like to see happen in treatment activism--what would ease some of your frustration?

It would be nice if drug-treatment activists really got together again. The International Conferences on AIDS have become a kind of drug-and-pony show, with drug companies showing off their new drugs, but no one talking about resistance. A real forum on resistance--not run by a pharmaceutical company--would be so helpful.

Do you think issues of resistance have been ignored by those involved in AIDS treatment and activism?

People have been saying that fear of AIDS is decreasing, that it’s now a manageable disease. That really upsets me--as someone living with AIDS and having to take multiple drugs every day, I can say that it’s no easy thing. Managing this is a full-time job. I’m still on disability, and I haven’t had a steady six months of consistently dropping viral load in the past three years.

I’m still here, and I thank God, but it’s been a struggle all along the way. I’ve had some great seasons, but my concern over my health has been consistent. The new drugs haven’t lived up to their promise for me. I’ve tried as hard as anyone to follow the regimens and do what I’m told. And just when I think, “Hey, this drug is working!” my viral load goes back up. It makes me wonder, “Why me?” If these things work for so many people, what kind of virus do I have, that it can fight absolutely everything?

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