Seeing the Big Picture

Taking care of your whole health is just as important as taking care of your HIV.

November 28, 2016 By Rita Rubin

To Rae Lewis-Thornton, staying healthy entails much more than just taking her antiretroviral (ARV) medications without fail.

“People with HIV need to understand that it’s not just about your viral load and your CD4 count,” says Lewis-Thornton, who was diagnosed with AIDS in 1992. She learned she had HIV five years earlier when she donated blood at a drive she had organized. (In hindsight, she figures she was infected a few years before the blood drive screening confirmed it.)

In other words, just because your HIV is under control doesn’t mean you can ignore the rest of your health.

“It’s about managing all the components in your life,” Lewis-Thornton says.

Today, HIV medications make it easier than ever for most people to live long and healthy lives with the virus. But whether you’re starting treatment for the first time or are a long-term survivor, like Lewis-Thornton, you also need to take care of your whole health—your heart, liver, kidneys, bones, mind, etc.

For Lewis-Thornton, staying healthy means taking medication for an underactive thyroid as well as ARVs for her HIV. It means seeing a therapist and a psychiatrist for treatment of depression. It means working out regularly and trying to eat a well-balanced diet. It means knitting, reading, beading, sipping tea and playing with her poodle, Chloe, to help deal with stress and anxiety. It means tending to her spiritual life.

“I want to continue to be my best me,” says Lewis-Thornton, who’s an AIDS activist, a blogger (at RaeLewisThornton.com and on POZ.com) and author. She’s also a jewelry designer, political organizer, Emmy Award winner and ordained Baptist minister with a master’s degree in divinity.

The Chicago resident has come a long way from the first couple of years after learning she had HIV, when she wouldn’t even tell her doctor she had the virus.

In some ways, though, she had a head start on her road to health, Lewis-Thornton says. The nonsmoking daughter of an alcoholic mother and a heroin addict father, Lewis-Thornton never

acquired a taste for alcohol and never used drugs. (She says she contracted HIV when she was "looking for somebody to love me, looking for Mr. Right.")

Lewis-Thornton learned she had HIV before the advent of ARVs and has gone three rounds with pneumocystis pneumonia. She was on a "trajectory toward death," as she puts it, until AZT came on the market. She lost so much weight that her dress size dropped to zero. "I looked in the mirror and saw death staring at me," she says. Even so, when she transitioned to AIDS, she says, "I decided that I wanted to live as long as I possibly could." She was going to take care of herself to the best of her ability.

When effective HIV treatment became available in 1996, people like Lewis-Thornton began to realize that they could live decades with the virus, which meant they had to pay attention to their total health, especially as they got older.

Today, more than half of all people living with HIV in the United States are 50 years or older. When Lewis-Thornton was diagnosed a dozen years ago with endometriosis—a disorder in which tissue that normally lines the womb grows outside it—both she and her doctor chuckled. "Well," the doctor told her, "you've lived long enough to have an illness that has nothing to do with HIV."

Still, there have been times Lewis-Thornton automatically blamed health issues on HIV. Take the morning she awoke covered in sweat. She was scared, because she'd always associated night sweats with HIV-related infections. Her friends and her doctor had to point out that she was going through menopause and must have had hot flashes while she slept. After all, she is 54 years old.

"For a long time, I didn't consider that I would have issues of aging," Lewis-Thornton explains.

Even if HIV isn't the cause of a health problem, it might not be totally blameless. While HIV doesn't trigger the hot flashes of menopause, it might make them more severe, Lewis-Thornton points out. In addition, the combination of HIV and ARVs exacerbates osteoporosis, the bone-thinning disease that can occur as women (and, less commonly, men) age. "Women with HIV have to be very careful when it comes to maintaining good bone health," she notes. She deals with "really bad" irritable bowel syndrome that, she says, could be related to the early HIV medications she took, at one point totaling 32 pills a day.

Lewis-Thornton is fortunate that Chicago's Cook County Health and Hospital System is the home of one of the country's first clinics for women and children with HIV. Its "one-stop-shopping" approach provides all needed services, including gynecology and psychiatry, in one place, making it easier for her and other patients to take care of their whole health.

Lewis-Thornton makes the most of the clinic's services. She doesn't ignore symptoms, and if she's not sure about what's causing them, she makes a doctor's appointment to have them checked out. Plus, she gets regular screenings for breast cancer and cervical cancer.

Cancer screening and other preventive health care measures appear to be especially important for people with HIV. For example, while HIV increases women's risk of developing and dying of

cervical cancer, regular screening can greatly cut the risk.

People with HIV also appear to have a higher risk of coronary heart disease than people who are not infected, although that seems to be due in part to a greater likelihood of having risk factors such as smoking. A recent study concluded that among Medicare beneficiaries 65 and older, people living with HIV were more likely to have chronic diseases such as diabetes and arthritis than people who were not living with the virus.

Starting HIV treatment early may lower the risk of several conditions not usually tied to HIV infection—such as heart, liver and kidney disease, as well as a variety of cancers.

These research findings highlight the need for people living with HIV to heed Lewis-Thornton's advice and look at their total health picture, not only the HIV part.

"I don't want to just be alive," she says. "I want to live well with HIV."
