Living Long-Term With HIV

Thanks to today's antiretroviral treatment, people with HIV can live longer than ever. But the ultimate goal is to thrive, not just survive. Here, we offer inspiring tips and solutions to help you live your life to the fullest.

September 5, 2016 By Benjamin Ryan

When Art Jackson was diagnosed with HIV in January 1989, a doctor told him that he might last only another three months and should get his affairs in order. He was just 24 years old. He got on a bus in New York City, where he was living at the time, and traveled to Orange, New Jersey, to see his beloved mother and tell her the devastating news.

"Mom, I'm gonna die. I'm gonna die," he recalls repeating to her through his sobs. "She let me cry for about an hour and a half or two hours, and she just held me."

Eventually, he'd cried so much there were no tears left. At this point, his mother asked him, "What are you gonna do?" She kept posing the same question as he repeated the refrain: "I'm gonna die."

"OK, but in the meantime, until you do," he remembers her saying, "what are you gonna do? Sometimes all you can do is live. Sometimes there's gonna be a second at a time. Sometimes there's gonna be a minute at a time—that's all you can do. You could try to live the best life that you can. You've always lived with your head up. If you gotta go out, go out with your head up. Let them see you shine."

Jackson, who is now 51, took his mother's wise counsel very much to heart. To this day, he tries to live by those words. He's devoted his life to giving back, educating others about HIV both through direct instruction and by example. He works as a health educator and community programmer at Community Health Interventions in Fayetteville, North Carolina, where he promotes HIV prevention, education, testing and care. One of his many HIV-related volunteer ventures includes developing a program called PRIDE, in which he works with young people ages 13 to 25 on making healthy decisions in life.

He's a 27-year survivor of HIV who's never actually been sick with any conditions related to the virus and has never been hospitalized. In fact, he sees a silver lining in living with HIV.

"Becoming HIV positive—it may sound crazy, but I honestly think that it saved my life in a lot of ways because it focused me," Jackson says. "It gave me a new direction. And because of that, I

was able to find my passion, and that was helping others."

During the past two decades, which are recognized as the modern era of effective combination antiretroviral (ARV) treatment for HIV, the expected life span of people living with HIV has been steadily marching toward that of their HIV-negative peers. And even though there's still on average about a 14-year gap between the two groups, HIV-positive people can narrow this gap considerably if they maintain more than 500 CD4 cells (a sign of good immune health), treat coinfections with hepatitis B or C viruses (HBV/HCV), don't smoke and don't abuse drugs or alcohol.

As a result of this ever-improving longevity (as well as people contracting the virus later in life), an estimated half of U.S. residents living with HIV are now older than 50, according to the Centers for Disease Control and Prevention (CDC). And by 2020, perhaps as much as 70 percent of the nation's HIV population will fall into this age group.

An increasing proportion of people living with HIV are taking ARVs and maintaining a fully suppressed viral load. And after years of uncertainty about the ideal point at which to start HIV treatment, the jury is in: It's best to treat the virus as soon as possible after diagnosis. Treating HIV earlier rather than waiting until CD4 levels drop is linked with a reduced risk of various illnesses as well as death.

For people on successful ARV treatment, the primary focus has shifted away from managing HIV and toward keeping healthy in other areas, in particular working to prevent conditions related to aging, such as heart disease, which the virus can apparently help prompt. In other words, it's important for people living with HIV to look after their overall well-being, not just their HIV.

The main point isn't just to stay alive with the virus, it's to thrive, to live a full and well-rounded life.

Doing so can be a tall order when numerous other life stressors compromise your ability to take care of yourself. In this POZ Focus, we take a look at some practical solutions to help you manage HIV, like getting to your routine doctor visits and adhering to your ARV regimen and other medications you might be taking. (Adherence means taking your meds as prescribed.) This special issue of POZ will also focus on how to find the kind of support you may need to give you the opportunity to live your best life.

"The people I see who are doing the best are people who don't define themselves by having HIV or by having any other medical problem," says Joel Gallant, MD, medical director of specialty services at Southwest CARE Center in Santa Fe, New Mexico. "They're living a really full life. They're often working, or they're retired and staying really busy. Their life is much bigger than a collection of medical problems."

David Hardy, MD, an HIV specialist at Whitman-Walker Health in Washington, DC, says he tries "to create a mindset of healthy living" with his HIV patients. He hopes to shape their perspective on becoming HIV positive so they can actually benefit from the transition just as Jackson has. Hardy

frames the news “as a wake-up call to look at their lives in a new and different way, to really turn it on the positive, looking at the fact that because of HIV, they now consider other healthy lifestyle habits.”

A fundamental healthy habit is, of course, seeing a physician for routine HIV care. (If you don’t have health insurance, you may be able to find affordable coverage through Obama-care. Visit HealthCare.gov for more information.) These days, if you’re doing well on your ARVs, you may not need to have CD4 and viral load testing done every three months, as has long been the standard. However, even if your HIV is well under control, there may be other reasons to keep in close contact with your health care professional, especially as you get older. So carefully discuss with your provider how often you need to see him or her and whether there are other medical specialists you may want to see as well.

In his medical practice, Hardy has his patients come in for a blood draw eight to 10 days before their checkup so that he has all necessary test results in front of him when he sees his patients. If getting to your doctor’s office isn’t very convenient, you could ask your doctor whether an independent lab closer to your home might draw your blood and send him or her the results. That way you have to make a big trip only for the office visit itself.

Of course, many people find that simply getting to the doctor is a challenge. They may not have access to transportation, and getting a ride with someone could mean effectively disclosing their HIV status when they are not comfortable doing so. Consider asking your doctor’s office for help with transportation solutions.

Your health care team may also be able to provide other kinds of support, such as nurses who can answer questions about medications and side effects, substance abuse counseling and case management. So make sure to ask what more the team can do for you outside of what happens during your face time with the doctor.

Numerous communities across the United States have AIDS service organizations (ASOs) that can also help people living with the virus in various ways, including securing housing support, connecting with health care, food pantry services, transportation, case management and mental health and substance abuse treatment. To search for such support and to find lists of other HIV-related service providers, visit directory.poz.com.

As people with HIV get older, they may be at particular risk for social isolation, especially those who retired relatively early in life. Loneliness is an epidemic that increasingly affects the American population at large; research has found that it can be a major drag on physical, not just psychological, health.

“Isolation often leads to depression, and depression leads to poor adherence [to medications], and poor adherence can lead to bad things,” Hardy says. (See sidebar for more on adherence.)

In addition to seeking out support groups or social groups, such as sports teams, Hardy

recommends looking for the kind of volunteer opportunities that have been so fulfilling to Jackson. Becoming involved in your community like this can open you up to new friends and instill you with a greater sense of purpose.

Scott Kramer, LCSW-R, a psychotherapist in New York City who runs support groups for people living with HIV, was inspired to start his groups by one that he joined in 1995 as he was grappling with his AIDS diagnosis. “That group really saved my life,” he recalls. “It gave me community, it gave me friendship, and it gave me something to do on a Friday night that wasn’t related to going out to a bar. I met some wonderful people.”

Loren Jones, 64, a Berkeley, California, resident who tested positive in 1985, counsels others living with the virus: “No matter what your situation is starting out, if you could just be brave enough to connect with an organization or with people who are HIV positive, we do have a lot of positive ways to help people. Because anything that’s out there that you’re going through, there is probably somebody in your area who has been through the same thing. There are people who can help you, there are people who could support you, there are people you can talk to. You don’t need to be afraid. I think that the main thing is to not be alone because you don’t need to be.”

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