Living & Aging with HIV: What It’s Like & What We Need to Do

An advocate, educator and long-term survivor on self-empowerment.

September 16, 2014 By Mark Milano

Mark Milano

When I was diagnosed with AIDS in 1982, I had little idea what my prognosis was or even what the word meant. I only knew that there was no treatment and that I would have to survive on my own.

Now, 32 years later, I'm 58 and still determined to beat this thing. But aging with HIV has been a challenge, to say the least. I'm the poster boy for HIV comorbidities — I'm not only dealing with HIV, but also with metastasized anal cancer, high blood pressure, a heart condition known as tachycardia, kidney damage, sarcoidosis, erectile dysfunction, peripheral neuropathy, and gastroesophageal reflux disease. How's that for a bag of tricks?

ACRIA's Research on Older Adults with HIV study found that we have, on average, three times more comorbid conditions than our peers without HIV. Managing all these illnesses takes a tremendous amount of energy — I seem to have a doctor’s appointment every week or so, and am constantly running to a new specialist to see how to handle whatever new symptom or abnormal lab result has popped up.

But I refuse to let all this get in the way of living. I work full time, I’m at the gym every other day, have an active social life, and still raise hell in the street with ACT UP and Queer Nation.

Unfortunately, many older adults with HIV are not as self-sufficient and empowered as I am. And many of them lack the social support networks that other seniors have, due to friends lost to AIDS and a lack of family support.

That’s where the various support agencies come into play — they offer the vital assistance many older adults with HIV need in order to manage the numerous conditions they’re dealing with. My cancer diagnosis threw all this in stark relief for me. When I was thrown into the world of cancer care back in 2007, I found it to be very different from the world of HIV. At first, I got referrals to cancer specialists, but when I called, they wanted me to wait a month for an appointment! What? Let this thing spread for a month before even seeing someone? No way. Luckily, my HIV doc intervened and got me into the NYU Cancer Center in a few days.

Source: Acria

But the responsibility on me was enormous. All along the way, I was expected to manage my care myself — making all the appointments, checking on my insurance coverage, learning about treatment options. Once again, virtually no hand-holding. I wondered how people with less experience as a self-advocate — people who aren’t able to be as much of a “squeaky wheel” as me — would fare in this system.

Luckily, I had years of experience advocating for myself, because of having HIV. The day I was diagnosed, I joined the Yahoo anal cancer support group and found incredibly well-informed, caring people who did everything they could to help me out. What a godsend. It was here that I learned much of what I needed to know about how to get through treatment. Many of the radiation side effects (impotence, infertility, hair loss, etc.) were never discussed by my doctors. I brought them up with my doctors after learning about them from the support group. Numerous tips and tricks for dealing with the side effects once again came from the group and not my doctors — to this day, I'm shocked by how my care providers minimized or ignored the potential side effects.

In work as an HIV treatment educator and counselor, I'm constantly reminded how critical personal empowerment is in battling this disease. I've seen clients go from being in a state of denial to being full-fledged advocates for themselves and others. It's critical that we continue this work to ensure that all older adults with HIV get the care they need.

Mark Milano is an editor, writer, and educator at ACRIA. He is also a member of ACT UP New York, Health GAP, and the AIDS Treatment Activist Coalition. He lives in New York City.

September 18 is National HIV/AIDS and Aging Awareness Day (NHAAAD). To commemorate NHAAAD 2014, ACRIA will be hosting an open house. Click here for more information about the event.
