Sanctuary for Survivors

A Friends In Deed program called LTS offers support to HIV long-term survivors and addresses three specific issues: aging, isolation and meaningful relationships.

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Jon Jay Read

Yet another of my friends has gone off his HIV medications. I ask, but he doesn't know why, exactly; or maybe it's just that he can't find words more specific than these: "The good news is, AIDS didn't kill me. The bad news is, AIDS didn't kill me."

Twenty-five years with the virus, and for some reason he's giving up now.

It's obvious to anyone paying attention that something other than HIV is plaguing many of us long-term survivors. For a decade, if not longer, this insidious thing and its various components—loneliness, disappointment, lack of purpose—have churned at our core. Discussing it effectively is difficult, because the thing itself is so ill-defined and poorly understood; in fact it isn't one thing at all, but rather a complex of interwoven issues:

1. To begin with, we are traumatized, having lived through what was, in essence, a war. We lost an incomprehensible number of friends, and nursed too many loved ones through the dying process—suspecting all along that their physical and emotional suffering foreshadowed our own. If not for AIDS, those men would now be reminiscing with us over coffee. We'd be pushing one another's buttons, poking awake long-forgotten grudges, recalling illicit flings, sharing inside jokes. But they are gone, and we are … "old." Worse yet: Old Gay Men. Might as well say, "spinsters."

2. We are sinking further and further into poverty, weighed down by menacing piles of documents written in a legalese no normal human can comprehend, and from which we're certain no happy news will come. Getting our heads above water, financially, is challenging both because we must document our destitution in order to qualify for essential benefits, and because few employers are eager to hire 60-year-old men with 20-year gaps in their resumes.

3. Some of us are experiencing physical maladies one would expect to find in men decades our senior: osteoporosis; cognitive difficulties; heart, liver and kidney disease. It's not always clear which are caused by medications, which by the virus itself. What is clear, though, is that managing our health keeps us trapped: tied to clock and geography; to pharmaceutical companies who recognize a frightened and desperate cash cow when they see one; and to insurance mega-corporations we know in our marrow would rather we just die and leave them their profits. As a

group, we are both lucrative and expensive. Rope in a tug-of-war between boardrooms.

These issues, along with myriad others, are responsible for the increase in depression and suicide rates among long-term survivors. Undoubtedly they have contributed to my friend's decision to cease taking his HIV medications. It's obvious that something must be done. But what?

One organization trying to find answers is Friends In Deed: The Crisis Center for Life-Threatening Illness, a nonprofit based in New York City. With funding from the Elton John AIDS Foundation (EJAF) Friends In Deed created and implemented a six-month-long pilot program for gay male long-term survivors. Comprised of workshops, weekly discussion groups, an immersive weekend retreat, individual counseling, and opportunities for socializing, the pilot was completed in June 2014.

Jon Jay Read's "Morning Dose"

Analysis of data collected during pre- and post-participation interviews has provided a wealth of information. For example, the act of being together with other long-term survivors was, in and of itself, healing. The men found comfort in telling their stories and sharing feelings without being met by expressions of apathy and confusion—or worse yet, with the questions that have become all too familiar: "You just take a couple pills, right?"; "You look well, so why aren't you working?'; and "Is aging with HIV really so different than aging without it?"

By program's end, a majority of the men felt less stigmatized; and most came to believe that painful as AIDS was, it also engendered wisdom, resilience, and an awareness of what it is to love and be loved in deep and profound ways.

In January 2015, a revised version of the program will be launched. Shorter (three months long) and altered according to feedback indicating what did and did not work previously, the new program is titled LTS (for Long-Term Survivors). Once again funded by the EJAF, LTS will address three specific issues: aging, isolation, and meaningful relationships.

It is open to all gay male long-term survivors in the New York City area. (The hope is to expand to other cities in the future). Participation requires a telephone screening as well as a one-hour, in-person interview. Those interested should call 212-925-2009 or email jread@friendsindeed.org with the subject "LTS POZ." In addition to this program, Friends In Deed provides a weekly discussion group for long-term survivors, 5:30 to 6:45 p.m. every Thursday. Click here for more information on the group.

For 20 years, Jon Jay Read, or "Read," LMSW, has been the director of client services at Friends In Deed: The Crisis Center for Life-Threatening Illness. Visit friendsindeed.org for more info.

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