



OLDER PEOPLE LIVING WITH HIV

Three decades ago, people who were diagnosed with HIV could expect to live only one to two years after their diagnosis. They were more focused on if, when, and how they would die, rather than how they were going to live.

People living with the disease were not focused on—or prepared for—what life would look like even a handful of years ahead. Neither were the doctors, care providers, or government programs serving them. Today, older people (age 50+) living with HIV are a growing population with pronounced needs.

The Aging of the Epidemic

According to the latest CDC Surveillance Report from 2017, nearly 50 percent of people living with HIV in the United States are 50 or older. People 50 and older also accounted for 17 percent of new HIV diagnoses in 2017.

Research indicates that older Americans are more likely than younger Americans to be diagnosed with HIV late in the course of their disease, meaning they are more likely to be dually diagnosed with HIV and AIDS. This late diagnosis and the consequent late access to treatment results in more and more severe health complications. This can lead to poorer prognoses and shorter survival rates after diagnosis.

Pronounced Health Challenges

The U.S. Department of Health & Human Services (HHS) reports that those living with HIV for many years exhibit many clinical characteristics



commonly observed in aging, including multiple chronic diseases or conditions, the use of multiple medications, changes in physical and cognitive abilities, and increased vulnerability to stressors. While effective treatments have decreased the likelihood of AIDS-defining illnesses, such HIV-associated non-AIDS conditions are more common in individuals with long-standing HIV infection.

Poverty and Social Isolation

Upon diagnosis, most didn't expect that they would live to see another year. Many cashed in their savings, retirement plans, and life insurance policies to pay for their immediate health needs. As the groundbreaking *San Francisco Chronicle* project "Last Men Standing" helps to illuminate, many long-term survivors are living lives they didn't plan or prepare to live.

Long-term survivors have relied for decades on government-funded disability programs. And now,

as they cycle off disability support and onto Social Security, they have scant work histories to justify more than a minimal Social Security check. On top of these already difficult financial challenges, many continue to live in cities with skyrocketing housing and living costs, like San Francisco and New York.

Having lost many of their friends during the epidemic, many find themselves having thin social support networks and being without connection to their families of origin. Long-term survivors report that they feel culturally and socially isolated, lacking the support networks that become all the more critical as all people age.

Ageing Network and HIV Providers Ill-Equipped to Address the Ageing of the Epidemic

Neither survivors themselves nor HIV- and LGBT-focused providers sufficiently planned for the ageing of the epidemic. Policy makers, health care providers, and ageing providers can and must do more to take on the challenges presented by the ageing of the epidemic, including expanding cross-training and coordination to build HIV-and-ageing cultural competencies and bolster the HIV-and-ageing provider workforce.

Congressional Support

Congress must act to ensure that federal policies acknowledge that older people are both living



with and continue to be at risk for HIV; that those at risk are made aware that they are at risk and are offered testing; and that older people living with HIV have access to the culturally competent services and supports that are necessary for them to both thrive and remain independent. Congress must require the National Institutes of Health to engage in a targeted and coordinated cross-division research effort, including research on psychosocial issues and non-medical supportive services, for at-risk older people living with HIV. Congress must also require the CDC to engage in targeted prevention and treatment messaging for older people.

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Advocacy &
Services for
LGBT Elders

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SAGE is the country's largest and oldest organization dedicated to improving the lives of lesbian, gay, bisexual, and transgender (LGBT) older people. Founded in 1978, SAGE is a national organization that offers supportive services and consumer resources to LGBT older people and their caregivers. SAGE also advocates for public policy changes that address the needs of LGBT elders, provides education and technical assistance for aging providers and LGBT community organizations through its National Resource Center on LGBT Aging, and cultural competency training through SAGECare. With staff located across the country, SAGE also coordinates SAGENet, a growing network of affiliates in the United States.

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