

Educating caregivers of people ageing with HIV



Lancet HIV 2026

Published Online
July 27, 2026
[https://doi.org/10.1016/S2352-3018\(26\)00141-4](https://doi.org/10.1016/S2352-3018(26)00141-4)

See Online/The Lancet HIV
Commissions
[https://doi.org/10.1016/S2352-3018\(26\)00058-5](https://doi.org/10.1016/S2352-3018(26)00058-5)

The Lancet HIV Commission on Ageing and HIV: a global perspective represents a milestone in HIV care. By including the voices of researchers, clinicians, and people with lived experience, the Commission has created a template for reconfiguring the care of people ageing with HIV.¹ A key message is the importance of care integration and creation of partnerships with all key stakeholders, including informal caregivers, who are “relatives, friends, partners, or neighbors who provide assistance, typically unpaid, to someone who has limitations in their physical, mental, or cognitive functioning.”²

Caregiving is a fundamental human need, and many of the concerns of caregivers supporting people ageing with HIV are no different from those of caregivers supporting people without HIV: what will my role be in this person’s life and how will it change; what are my loved one’s medical problems and how do I help them manage; and how do I help them thrive without jeopardising my own health?

In addition, living with and alongside HIV presents unique challenges to both caregivers and the people they care for. What caregivers learn about HIV can be determined by the health-care establishment, but is influenced by the lived experience of their care recipient.

The stigma surrounding a positive HIV diagnosis can inhibit people with HIV from disclosing their status to the caregiver,³ and lead them to restrict what they want their caregiver to know. When a caregiver is identified, a patient–clinician discussion regarding the disclosure of their HIV status to the caregiver is essential. Understanding what the patient feels should and should not be shared with the caregiver establishes a culture of respect that can improve communication and comfort and address the stigma itself. Even when patients have established trust with their caregiver, disclosure can be an ongoing worry, especially in situations with paid caregivers or staff at long-term care facilities, where people with HIV might be concerned about discrimination if their HIV status or sexual orientation is disclosed.⁴ Finally, caregiving itself for someone with HIV can be stigmatising; affiliative stigma is common⁵ and can contribute substantially to caregiver burden.

Caregivers who are unaware of the care recipient’s HIV status can learn about topics related to healthy ageing

(eg, individual comorbidities, the value of exercise and diet, and sources of caregiver support), but can and should be directed to general resources focused on the comorbidity or syndrome, rather than within the HIV context. Caregivers who know their care recipient’s HIV status can benefit from these general resources and HIV-specific information. The following topics are fundamental.

Toolkits and tips for caregivers regarding caregiving basics, including advice about respite, preventing social isolation and caregiver fatigue, and home safety are available from non-profit organisations and government websites. Websites focused on specific comorbidities (eg, coronary artery disease, cognitive impairment, or depression) often also have information for caregivers.

Caregivers should understand the impact of HIV on ageing and the key role of viral suppression on health maintenance. Caregivers might be surprised by the medical needs of a person who they perceive to be too young to experience comorbidities related to older people without HIV, and should recognise that HIV can advance ageing and lead to higher rates of multimorbidity. If empowered by the person with HIV to take an active role during clinical encounters, caregivers should be aware of potential drug–drug interactions and the importance of questioning subspecialty providers about the value and risk of introducing new medications.

Caregivers should understand that people ageing with HIV have a higher risk of cognitive impairment, even as effective HIV treatments have decreased the burden of HIV-associated brain injury.⁶ Caregivers can encourage people with HIV to address modifiable medical factors such as vascular disease and treatment adherence, and can also help mitigate structural limitations such as poor access to care and social isolation. Cognitive impairment is another condition with intersectional stigma that older people with HIV face,⁶ and caregivers can learn how to offer reassurance, maximise function, and help to ensure safety.

Geriatric syndromes such as frailty and falling, which do not have simple organ-based explanations, have greater impacts on quality of life for people with HIV.⁷ Caregivers can be trained to assess the care recipient’s

level of function, promote home safety awareness, and recognise when changes occur.

The mental health needs of older people with HIV require the substantial provision of health-care and social services. Caregivers might not have an in-depth understanding of their care recipient's needs, as it is likely that they will not be present during encounters with mental health professionals. Caregivers can learn to offer connection and support⁸ and recognise changes in affective status. Caregivers' mental health should also be addressed and prioritised.

Caregivers can play a role in promoting advance care planning. They can encourage the person with HIV to talk with their clinician about designating a health-care agent, and they can discuss their care recipient's health-care wishes.⁹ Documenting advance care plans is specific to jurisdiction; caregiver education needs to take local laws into account. Advance care planning discussions have the added benefit of encouraging the caregiver to think about their own advanced care planning needs.

As they age, people with HIV might develop functional or cognitive deficits that are too profound to manage at home and could require long-term care within institutions. Caregiving does not cease once an individual no longer lives in the community. Even if not performing physical caregiving roles, caregivers still play an important role in reducing loneliness, advocating for the people with HIV's rights and dignity, and ensuring that the loved one's health issues are addressed.

There are many opportunities for educational innovation. Within the clinical setting, staff can create learning opportunities and support groups for caregivers. Centres in the USA that create curricula for professionals, such as the Ryan White HIV/AIDS Education and Training Center or the National HIV Curriculum, should be funded

to create training curricula, videos, and handouts for caregivers. Many of the knowledge and skill domains that are appropriate for community health workers¹⁰ overlap with those of caregivers. Institutions that train community health workers should adapt and offer relevant programmes to caregivers as well, who are essential members of the health-care team.

MJG reports royalties from UpToDate. EEF reports honoraria from the Northeast Caribbean AETC. CJ is supported by the US National Institute on Aging (K23 AG 072960). All other authors declare no competing interests.

Eugenia L Siegler, Atami S De Main, Emily E Frey,
Carrie D Johnston, Marshall J Glesby
els2006@med.cornell.edu

Division of Geriatrics and Palliative Medicine, Weill Cornell Medicine, New York, NY 10065, USA (ELS, ASDM, EEF); Division of Infectious Diseases, Weill Cornell Medicine, New York, NY, USA (CDJ, MJG)

- Justice AC, Althoff KN, Clarfield AM, et al. The *Lancet HIV* Commission on ageing and HIV: a global perspective. *Lancet HIV* 2026; published online July 27. [https://doi.org/10.1016/S2352-3018\(26\)00058-5](https://doi.org/10.1016/S2352-3018(26)00058-5).
- Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family caregiving for older adults. *Annu Rev Psychol* 2020; **71**: 635–59.
- Moody K, Verburgh ML, Stutterheim SE, et al. Stigma-related disclosure concerns and negative self-image have not improved over a decade in older people with HIV. *J Acquir Immune Defic Syndr* 2025; **100**: 265–73.
- McMillan JM, Dalere J, Naqvi F, et al. Perspectives on continuing care, from home care to long-term care, for older people living with HIV: a cross-sectional study. *Health Sci Rep* 2025; **8**: e70578.
- Knowlton AR, Nguyen TQ, Isenberg S, et al. Quality of life among caregivers of a vulnerable population living with HIV: caregiving and relationship factors. *AIDS Behav* 2021; **25**: 360–76.
- Cysique LA, Levin J, Howard C, et al. Fostering healthy cognitive ageing in people living with HIV. *Lancet HIV* 2024; **12**: e71–80.
- Zhabokritsky A, Falutz J. Frailty in people with HIV: a geriatric syndrome approach to aging with HIV. *Curr Opin HIV AIDS* 2025; **20**: 344–49.
- Ahmed A, Taylor J, Lai JC-J, et al. 'It's not just HIV anymore': a qualitative exploration of health, research, community and mental health priorities of long-term survivors of HIV in the United States. *AIDS Care* 2026; **38**: 506–20.
- Maragh-Bass AC, Hendricks Sloan D, Aimone EV, Knowlton AR. 'The woman gives': exploring gender and relationship factors in HIV advance care planning among African American caregivers. *J Clin Nurs* 2021; **30**: 2331–47.
- Crowley JS, Grisham K. People with HIV as community health workers. 2024. <https://oneill.law.georgetown.edu/wp-content/uploads/2024/09/QT-HIV-Peers-as-CHWs.pdf> (accessed April 22, 2026).

For more on the **Ryan White HIV/AIDS Education and Training Center** see <https://aidsetc.org>

For more on the **US National HIV Curriculum** see <https://www.hiv.uw.edu>